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The Lived Experience of Parents Caring for a Child With Type 1 Diabetes

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ABSTRACT

Type 1 diabetes is the most common chronic metabolic condition seen in children and adolescents. Parents of children with Type 1 diabetes are responsible for carrying out a demanding treatment regimen on a daily basis, to prevent short- and long-term complications related to blood-sugar control. Parents can experience significant stress related to this role, but there is limited in-depth qualitative research on the parental experiences of caring for a child with Type 1 diabetes. Understanding the experiences of parents can contribute to better parental and child adjustment to the illness. The present study explored parental experiences by using Interpretative Phenomenological Analysis (IPA) of in-depth semi-structured interviews with 17 parents of children with Type 1 diabetes.

In this study, parents experienced a profound biographical disruption from the moment their child was diagnosed, which undermined their confidence in the ability to care for their child. Parents likened this to the experience of having a new baby. They used repair structures to reconstruct parental identity based on the idea of normality. These involved normality through typical childhood experiences, embracing a new normality, and preserving family normality. Looking after a child with diabetes was also dominated by the 'constant-ness' of the disease, driven by a need for constant vigilance and better management in the context of an unpredictable body. Parents responded to some of the embodied experiences of the child through their own embodied acts of caregiving. They also made comparisons between diabetes and other conditions as a way of coping with the embodied unpredictability of childhood diabetes. Parents' accounts of resilience in the context of Type 1 diabetes reflected a mainstream understanding of resilience as an individual attribute or capability.

However, from their talk of navigating through daily challenges, an alternative conceptualisation of resilience for these parents is presented as 'doing' resilience. 'Doing' resilience also involved a separation of actions and emotions of the parents, which supported the daily 'doing' of diabetes. These findings highlight the psychosocial implications of parenting a child with Type 1 diabetes. They indicate a need to acknowledge the profound impact on the parents' lives and the ways that they attempt to cope with the demanding caregiving responsibilities. Understanding these lived experiences can enable health professionals to provide better support in making sense of and coping with the changes in parents' lives.

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DEDICATION

To Mahin and Myran

Always keep your dreams alive. I know you can make them happen.

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PREFACE

The thesis is in the form of a thesis with publication. The first chapter presents an introduction to the present research by providing relevant background literature. Chapter 2 provides a detailed account of the methodology undertaken. Chapters 3, 4, and 5 present the findings of the analysis written up as individual manuscripts. Chapter 6 discusses the main findings and implications arising from the research, reflexivity, methodological considerations, and suggestions for future research. For readability, references have been provided at the end of each chapter.

The first manuscript has been published online in the *Journal of Child and Family Studies* (2017). The second and third manuscripts will be submitted for publication. As the three publications are based on the findings from one single study, some repetition in each of the manuscripts was anticipated, especially in the introduction and methodology sections.

My supervisors Dr. Mary Breheny, Dr. Kirsty Ross and Dr. Joanne Taylor provided guidance and feedback on the manuscripts, similar to their assistance with the other chapters of this thesis. Hence, they are included as co-authors for the publications included in this thesis.

CHAPTER 1: INTRODUCTION

Chronic Conditions of Childhood

A chronic childhood illness is generally defined as an on-going medical condition that requires long-term medical care and follow up (Jensen & Kazak, 2004). More specifically, chronic childhood illness has been defined as “any physical, emotional, or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment” (Van Cleave, Gortmaker, & Perrin, 2010, p.624). These can include conditions such as asthma, cancer, diabetes, sickle cell disease, epilepsy, juvenile rheumatoid arthritis, and HIV/AIDS. The prevalence rates of these conditions have increased over recent years (Perrin, Anderson, & Van Cleave, 2014). Over the past few decades, improved detection and treatments have enhanced the survival rates for children affected by different chronic conditions (Allen, 2010). In New Zealand, it is estimated that about 4 percent of children have disabilities related to conditions such as severe asthma, cerebral palsy, diabetes, or other chronic conditions (Statistics New Zealand, 2007). In addition, the rise of obesity in children has led to the development of other chronic conditions such as Type 2 diabetes and cardiovascular diseases in children and adolescents (Barlow, 2007). Hence, the number of families involved in caring for children with chronic illnesses continues to increase.

Caring for a Child with a Chronic Condition

There is a substantial body of literature about the experiences of families of children with chronic conditions. This has been studied across many disciplines, providing different perspectives on the subject. While some studies focus on the experiences for families in managing specific conditions, others include a range of conditions (e.g., (Branstetter, Domian, Williams, Graff, & Piamjariyakul, 2008; Gannoni & Shute, 2009). This latter non-categorical approach allows for the exploration of common experiences across conditions.

Parenting a child with a chronic illness involves multiple experiences across defined stages. The time of diagnosis marks a significant time where the family can experience strong emotional reactions. These can range from shock and grief, to relief at finally receiving an explanation for the child’s health difficulties (Cashin, Small, & Solberg, 2008; Coffey, 2006; Nuutila & Salanterä, 2006). During this emotionally difficult time, parents are inundated with information regarding the medical management of the condition and the potential long-term implications (Gannoni & Shute, 2009). It is

important that health professionals consider caregivers' concerns with respect and provide open and direct information to help parents navigate this critical time (Browning, Schlomann, & Schmitke, 2012). Kepreotes and colleagues (2010) have also emphasised how parents need accurate and timely information provided in an understandable, accessible, and supportive manner.

In the period following diagnosis, parents often go through a steep learning process where they learn disease management skills for the specific condition. The caregiver must also learn to identify and respond to illness symptoms, such as signs of hypoglycaemia or respiratory distress (Browning et al., 2012). Parents are challenged as they adjust to balancing the demands of illness management with those of everyday life. They are required to coordinate speciality health care and engage with a range of systems such as schools, insurance companies, and government agencies (Christian, 2010). In addition, as the child grows, caregivers need to exercise a balance between adequate supervision and overprotection, in the gradual process of shifting care responsibilities to the child, according to their readiness and ability (Browning et al., 2012). Parents described multiple ways of involving the child in collaborative decision-making regarding illness management, such as sharing information and asking for their opinion (Miller, 2009). Thus, in addition to the day-to-day illness management, parents also need to navigate developmental issues. These activities can result in substantial financial and time burden for caregivers, with implications for their employment and savings (Zan & Scharff, 2015).

Furthermore, the physical symptoms of the illness and disease management can interfere with the entire family's daily life (Barlow & Ellard, 2006). It can impact on family communication, roles and relationships. In one study, the stress of the chronic condition was found to contribute to disruptive, fragmented, distressed and insufficient communication between family members (Branstetter et al., 2008). Family roles and responsibilities shifted and siblings were seen to assume more adult role responsibilities (Branstetter et al., 2008). Studies reveal that parents worry about the impact of the illness on healthy siblings (Rehm, 2000). Stress related to caregiving can also cause tension in family relationships. Partners can experience marital strain as a result of different perceptions of the seriousness of the child's illness held by each partner (Rehm, 2000). Relationships with extended family can also be affected due to a lack of understanding of the child's condition (Gannoni & Shute, 2009).

Uncertainty can be a common experience for these families (Nuutila & Salanterä, 2006). Parents worry about the future when they are not able to care for the child (Murphy, Christian, Caplin, & Young, 2006). For parents caring for a child through long-

term treatment for a cleft palate, the cause and extent of the cleft was source of uncertainty, as well as the potential outcomes of treatment (Nelson, Kirk, Caress, & Glenn, 2012). Unpredictability in symptoms has been studied as an aspect of parental uncertainty (Dodgson et al., 2000). In highly acute conditions such as cancer, uncertainty can lead families to make the most of the present (Rehm, 2000). Parents also describe vigilance in their caregiving experience. This arose from a watchfulness to prevent harm to the child, underpinned by the uncertainty of the condition, and provided a way of gaining a level of control (Salfors & Hallberg, 2003). Vigilant parenting also reveals the intensive nature of caregiving, where one parent described it as 'mental monitoring' (Woodgate, Ateah, & Secco, 2008). This involved parents developing a sense of heightened watchfulness and preparation for action, in managing the uncertainty involved.

Families can also experience social and emotional consequences due to chronic illnesses. Parents described a loss of spontaneity as their family outings needed to be carefully planned (Gannoni & Shute, 2009; Waite-Jones & Madill, 2008). Parents caring for children with complex chronic conditions searched for social and physical environments that ensured the physical and emotional safety and comfort for all family members (Rehm & Bradley, 2005). Parents described feeling socially and spatially isolated due to the difficulty in leaving the house (Yantzi, Rosenberg, & McKeever, 2006). The sense of isolation has been described to arise from the lack of understanding of the condition within the society and sufficient support from extended family and health professionals (Woodgate et al., 2008). Parents highlighted the need to improve community awareness of the difficulties that come with chronic conditions (Gannoni & Shute, 2009). For parents who worked outside the home, even though being in employment provided them a certain relief from caregiving, this dual role is also associated with increased stress. Parents went to great lengths in trying to maintain their employment, such as working inconvenient and difficult hours while organising work hours around caregiving responsibilities (George, Vickers, Wilkes, & Barton, 2008). For caregivers, the increased responsibilities and resulting stress can negatively impact on their physical and emotional health (Cousino & Hazen, 2013; Harper et al., 2014; Yuwen et al., 2016). A lack of time and respite hours, lack of qualified alternative care providers and low prioritisation of need contributed to this negative impact (Murphy et al., 2006).

Health professionals can play an important role in helping parents care for the child with the chronic condition (Hummelinck & Pollock, 2006). Research indicates mixed findings of this support (Smith, Cheater, & Bekker, 2015). In one study, parents caring for a child with a physical long-term illness described that health professionals

provided practical advice that suited family needs, were available for support at any time, and encouraged parents to manage their own wellbeing (Nuutila & Salanterä, 2006). In contrast, parents caring for children with autism found health professionals unsupportive and lacking in knowledge and resources (Woodgate et al., 2008). Similarly, parents described feeling unacknowledged by healthcare workers, during stressful times for the family (Gannoni & Shute, 2009). The relationships between health care professionals and the family has been described as a complex 'web', where successful relationships are more likely when practitioners appreciate the uniqueness of each family (Dickinson, Smythe, & Spence, 2006).

While much of the literature points to the negative impact of caring for a child with a chronic condition, some studies have highlighted positive experiences and rewards involved in caring. Parents caring for children who required assisted ventilation at home described the irreconcilable tension between the distresses and enrichments involved in their experience (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). Parents also described positive emotions and increasing parental confidence when their child's treatment was progressing well and increased pride in the child for their efforts at self-management (Gannoni & Shute, 2009). Parents also highlighted positive effects on siblings such as greater maturity and empathy (Gannoni & Shute, 2009). Parents describe how relationships are also enhanced by the experience of chronic illness. In a study of Mexican-American parents caring for children with acute diagnoses such as cancer and cystic fibrosis, the mothers described how the normally close relationship between a mother and a child grew even closer after the child was diagnosed with the chronic condition (Rehm, 2000). These findings indicate that caring is a multifaceted experience involving both positive and negative experiences, and these can be competing at times.

In summary, families describe a range of experiences involved in caring for a child with a chronic condition. The time of diagnosis and developmental transitions are critical times when parents benefit from empathic and appropriate support suited to their particular needs. Parents' lives may be filled with uncertainty and vigilance, with implications for their social and emotional wellbeing. Nevertheless, parents may also engage in benefit finding, where they embrace positive experiences related to caregiving. Ultimately, health professionals working closely with these families are in an opportune role to find the best ways to support parents in their caregiving efforts.

Type 1 Diabetes

Type 1 diabetes is one of the most common chronic diseases of childhood (Atkinson, Eisenbarth, & Michels, 2014). It belongs to the group of diseases called diabetes mellitus, characterised by an impairment in carbohydrate and lipid metabolism (Goodman, 2012). Worldwide, the incidence of Type 1 diabetes has risen by 3.4% annually during the years 1995-1999 (DIAMOND Research Group, 2006). The International Diabetes Federation (IDF) estimated that 86,000 children between the ages of 0-14 would be newly diagnosed with Type 1 diabetes in 2015 globally (IDF, 2015). In New Zealand, the Ministry of Health's (MOH) Virtual Diabetes Register estimated a prevalence of 1786 children with diabetes between the ages of 0-14 years, for the year 2015 (MOH, 2016). It has also been indicated that there are approximately 2500 children and youth aged 0-18 years with Type 1 diabetes in New Zealand (Diabetes Youth New Zealand, n.d.). Type 2 diabetes in this age range accounts for less than 10% of new cases in New Zealand (Jefferies, Owens, & Wiltshire, 2015). The incidence of Type 1 diabetes increases with age, with the highest incidence observed in children aged 10–14 years (Maahs, West, Lawrence, & Mayer-Davis, 2010). The higher incidence in this age group was also found in a review in the Auckland region (Derraik, Reed, Jefferies, Cutfield, Hofman, & Cutfield, 2012). A higher rate of incidence has also been reported for the Canterbury region (DIAMOND Research Group, 2006). This increasing incidence has resulted in more families being affected by this disease in New Zealand and worldwide. At present, there is no known cure or preventive measure against the onset of Type 1 diabetes (Todd, 2010).

Type 1 diabetes is characterised by an autoimmune-mediated destruction of pancreatic β -cells, causing absolute insulin deficiency (Zimmet, Alberti, & Shaw, 2001). The aetiology of Type 1 diabetes remains complex, with the current understanding that environmental factors such as infections trigger the autoimmune process in genetically susceptible individuals (Åkerblom, Vaarala, Hyöti, Ilonen, & Knip, 2002). The hormone insulin is responsible for the use of glucose in our bodies. A lack of insulin leads to glucose not being used in the body for energy, resulting in hyperglycaemia- an excess of glucose in the blood (Doyle & Grey, 2010). This can cause many difficulties and if left untreated can lead to coma or even death (Eiselein, Schwartz, & Rutledge, 2004). Diabetic ketoacidosis (DKA) is a serious condition that can develop during this time characterised by hyperglycaemia, acidosis (increased acidity in the blood) and ketonuria (excess ketone bodies in urine) (Usher-Smith, Thompson, Sharp, & Walter, 2011).

Treatment usually involves a regimen of insulin therapy, management of diet and activity levels, and glucose monitoring (Doyle & Grey, 2010). Most individuals would need more than one insulin injection per day or may be on an insulin pump, and monitor their blood glucose levels several times each day (Falvo, 2009). The ultimate goal of treatment is to maintain blood glucose levels within a certain range, in order to reduce the risk of future complications. The National Institute for Health and Care Excellence (NICE) recommends a target average blood glucose level range of 4-7 mmol/litre for children (NICE, 2015). Another target in clinical care is the glycosylated haemoglobin measure (HbA_{1c}), which provides an indication of the average blood glucose over the past eight to twelve weeks, and is used as an objective measure of glycaemic control (Nathan, Turgeon, & Regan, 2007; World Health Organization, 2011). The American Diabetes Association (ADA, 2015) recommends a target HbA_{1c} level lower than 58 mmol/mol (<7.5%) for children, whereas NICE (2015) calls for tighter control at 48 mmol/mol (6.5%) or lower for children and young people to minimise the risk of long-term complications.

Chronic high blood glucose levels can lead to an increased risk of developing ischemic heart disease, cerebral and peripheral vascular disease, chronic renal disease, visual impairment and blindness, as well as peripheral neuropathy (Eiselein et al., 2004). The Epidemiology of Diabetes Interventions and Complications (EDIC) study has demonstrated that the maintenance of normal blood glucose levels with intensive therapy delays the onset and slows down the progression of such complications (de Boer et al., 2011; Pop-Busui et al., 2009; White et al., 2008).

Within this treatment, hypoglycaemia presents an unpredictable and dangerous side effect of insulin therapy, where falling blood glucose level could cause progressive cognitive impairment, confusion and even coma in severe cases (UK Hypoglycaemia Study Group, 2007). The more common hypoglycaemia symptoms include paleness, shakiness, headache, sweating, dizziness, mood changes, blurred vision and lack of concentration (Ambler & Cameron, 2010). An alternative treatment to daily insulin injections with an insulin pump which provides continuous subcutaneous insulin infusion has been found to reduce severe hypoglycaemia and improve overall glycaemic control (Johnson, Cooper, Jones, & Davis, 2013; Pickup & Sutton, 2008).

Role of Parents in Type 1 Diabetes Management

Parents of children with Type 1 diabetes play a pivotal role in illness management, to reduce the chances of short- and long-term complications. Parents tend to be heavily involved in the daily management of the illness, which has a significant impact on family life (Whittemore, Jaser, Chao, Jang, & Grey, 2012). As most children cannot

independently carry out diabetes management, the importance of involving the entire family unit in their treatment and care has been emphasised (Silverstein et al., 2005). For parents, the daily demands of the physical management of Type 1 diabetes in a child can be incredibly challenging. Maintaining a child's blood glucose level at a healthy range can present a constant challenge, where carers need to closely monitor the child's activity, diet, insulin injections and their blood glucose levels. Parents continually monitor their children for symptoms of hypoglycaemia and hyperglycaemia and respond accordingly to resolve the symptoms and return the blood glucose level back to the normal range. Increased monitoring and additional management is required during periods of illness, which can generally raise blood sugar levels (Soni et al., 2016). Parents also play an important role together with the health care team in providing the child's school or day care centre with the necessary knowledge and guidelines to help the child participate fully and safely at school (American Diabetes Association, 2014). As parents play a vital role in maintaining the health of children with Type 1 diabetes, understanding their experiences of caring for their children can highlight the impact of the illness on the parents and their particular areas of need. This can contribute to enhanced knowledge that can improve support provided for them.

Psychological Experience of Parents Caring for a Child with Type 1 Diabetes

The majority of studies on childhood Type 1 diabetes have been conducted from a quantitative perspective. These have mainly focused on parental psychological distress, and outcomes such as health-related quality of life and glycaemic control. Clinically significant levels of anxiety and depression were reported by mothers of school-age children with Type 1 diabetes (Jaser, Whittemore, Ambrosino, Lindermann, & Grey, 2008; Jaser, Whittemore, Ambrosino, Lindermann, & Grey, 2009). Elevated levels of depression in parents were found to be correlated with poorer child health status as measured by HbA1c (Driscoll et al., 2010). Parental burnout was associated with psychosocial factors; a lack of social support, lack of leisure time, financial stress, and a perception that diabetes impacted everyday life (Lindström, Åman, & Norberg, 2011). Mothers reported a lower health-related quality of life and increased worry following the diagnosis compared to fathers (Jönsson, Lundqvist, Tiberg, & Hallström, 2015). Parents were also found to report a greater perceived impact of diabetes on the child's health-related quality of life than children themselves (Chaplin et al., 2009).

Increased parenting stress and anxiety were found to be associated with difficult child behaviour related to diabetes management, particularly around mealtimes and

bedtime (Hilliard, Monaghan, Cogen, & Streisand, 2011). Higher parental stress has also been associated with frequent night time blood glucose monitoring (Monaghan, Hilliard, Cogen, & Streisand, 2009). Some research has also examined parental fear of hypoglycaemia, proposing that parents may allow higher than optimal sugar levels to prevent hypoglycaemic episodes (Patton, Dolan, Henry, & Powers, 2007). This fear could be related more to the severity of hypoglycaemia, such as whether the child has had a hypoglycaemia-induced seizure in the past (Barnard, Thomas, Noyes, & Waugh, 2010). One study reported that parental fear of hypoglycaemia was correlated with poorer glycaemic control (Haughstvedt, Wentzel-Larsen, Graue, Sjøvik, & Rokne, 2010). These findings highlight the psychological distress and impact associated with caring for a child with Type 1 diabetes.

Some research has also sought to identify factors related to family functioning that may impact on diabetes management. Higher parent-perceived family cohesion was related to lower levels of parenting stress (Moreira, Frontini, Bullinger, & Canavarro, 2014). In another study, higher child-perceived family cohesion was found to predict better treatment adherence and glycaemic control (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004). These findings associate family cohesion to better diabetes outcomes.

Research has also evaluated the effectiveness of interventions for parents and children in coping with the condition. An online social support programme was found to increase parental self-efficacy, through facilitating information sharing and networking (Merkel & Wright, 2012). In another study, telephone-based social support was found to decrease parenting stress for parents of very young children with Type 1 diabetes (Monaghan, Hilliard, Cogen, & Streisand, 2011). However, coping skills training was not found to have any significant improvement in glycaemic control or quality of life, compared to a general educational intervention (Grey, Jaser, Whittemore, Joen, & Lindemann, 2011). These findings may indicate that parents perceive social support as more helpful than targeted teaching interventions for parents, suggesting that a better understanding of what parents find helpful for their coping is required.

Another intervention study, the DEPICTED study conducted in the United Kingdom, involved improving communication skills of health care staff working with children and carers (Robling et al., 2012). The study involved brief team-wide training of 79 health care practitioners in consultation strategies and communication skills. It was found that the training had no impact on glycaemic control of the children who received services from the trained practitioners, measured at one year following the programme. This finding indicates that glycaemic control is influenced by a variety of

factors and that a more contextualised understanding of these are required in supporting children and their carers.

While this body of research has contributed to knowledge regarding challenges and impact of caring for a child with Type 1 diabetes, it provides little insight into the unique experiences of parents as they adjust to and cope with the demands of the illness in their child. Using pre-determined measures of distress, adjustment, and coping reflects researchers' views rather than parents' views and provides a limited understanding of parental perspectives. Qualitative research on parental experiences aims to promote this perspective and provide a better insight into the multifaceted nature of caregiving.

A Review of Past Qualitative Research on Type 1 Diabetes

Qualitative studies on childhood diabetes aim to enhance the understanding of the experience of parents and caregivers with a child with Type 1 diabetes. Much of this research has been carried out within the nursing discipline, as nurses provide essential diabetes care and support for children with Type 1 diabetes and their parents. This growing body of research has important implications for those involved in supporting children with Type 1 diabetes and their families. A review of these studies provides important insights into the range of parental experiences.

Psychosocial Experiences of Parents

The time of diagnosis can be a particularly stressful time for families with a child with Type 1 diabetes (Lowe, Gregory, & Lyne, 2005). Feelings of guilt and remorse were reported by parents if the child had developed diabetic ketoacidosis at the time of diagnosis (Rankin et al., 2014a). Parents also described an 'information overload' at the time of diagnosis, and that their emotional state during this time was a barrier to comprehending all the advice given (Rankin et al., 2014b). Grief is a common emotion following the diabetes diagnosis (Marshall, Carter, Rose, & Brotherton, 2009; Whittemore et al., 2012). This initial grief reaction has been described to be similar to that commonly associated with bereavement. Marshall and colleagues (2009) found that, for the parents in their study, the grieving process ran a natural course, with the parents ultimately coming to terms with their loss. Interestingly, Bowes and colleagues (2009) describe a more sustained grief reaction or 'chronic sorrow' in relation to parents with children with Type 1 diabetes. Rather than grief associated with the diagnosis, they found episodic grief reactions, triggered at critical times during the child's development. This indicates that, as children develop, the losses associated with childhood diabetes change. These parental emotional experiences demonstrate a

range of initial responses and how some can persist over time due to developmental and situational demands.

A diagnosis of Type 1 diabetes may be marked by multiple losses. Parents have described the loss of their previously healthy child, their freedom, and a loss in their own confidence in parenting (Marshall et al., 2005). Parents have also expressed the loss of their child's independence and spontaneity (Lowe, Lyne, & Gregory, 2004). The sense of loss can be long lasting. In a study exploring parents' experiences of adjustment and adaptation over the first year after diagnosis, it was found that many parents were still cognizant about the loss of their healthy child, control, freedom, and confidence in protecting children from harm even after 12 months (Lowe et al., 2005). These findings suggest that parents not only suffer losses directly related to them, such as loss of confidence in parenting, but also bear those that impact on their children such as the loss of their independence. Furthermore, they also describe the experience of loss persisting over time.

On-going stress and worry can dominate the experience of caring for a child with Type 1 diabetes. Parents attribute the source of this stress to diabetes management and on-going worry about long-term complications such as a child's possibly shorter life expectancy (Bowes et al., 2009; Buckloh et al., 2008). On a daily basis, parents struggled to maintain blood glucose levels within target ranges, and acknowledged the impact of several factors outside of their control on blood glucose levels (Lawton et al., 2015a). A major source of stress also concerned parents having to regularly inflict pain on their child for blood glucose monitoring or insulin injections (Hatton, Canam, Thorne, & Hughes, 1995). They described this as going against their parental role to prevent harm and distress to their child (Whittemore et al., 2012). Parents have expressed relief and other benefits after switching to an insulin pump, as multiple painful injections were no longer required (Rankin et al., 2015).

For parents, the stress related to the fear of hypoglycaemia is also quite common. Mothers often worried about their vigilance to spot signs of hypoglycaemia (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). This was especially true for night time and naptime, and more so during the first few months after diagnosis. Responding to episodes of severe hypoglycaemia can be stressful and potentially traumatic (Driscoll, Raymond, Naranjo, & Patton, 2016). 'Hypoglycaemia unawareness' in a child can cause additional stress for parents, as they may not be able to respond quickly due to the delay or loss of initial hypoglycaemia warning signs (Driscoll et al., 2016).

Parents of children with Type 1 diabetes also commonly describe the heightened attention and workload that is involved in their care that contributes to increased stress. Mothers raising young children with Type 1 diabetes described being constantly vigilant (Sullivan-Bolyai et al., 2003). This behaviour was required to ensure that children were getting their insulin at the right times, that their diet and activity were appropriate and that their blood glucose readings were within the healthy range in order to avoid events of hyperglycaemia and hypoglycaemia. It was found that parents were unable to 'switch off' regardless of how old their child with diabetes was or their ability to look after themselves, as the constant checking provided the reassurance they needed (Marshall et al., 2009). Hence, constant vigilance is necessary, but nevertheless time-consuming and stressful. Further, parents described difficulties with careful planning of physical activities which conflicted with the unpredictable nature of children's activity (Quirk, Blake, Dee, & Glazebrook, 2014). These new routines associated with diabetes management may also impact on well-established routines within the family, adding further strain (Sparud-Lundin, Hallström, & Erlandsson, 2013).

Clinic appointments can be another source of stress for parents of children with Type 1 diabetes. Parents have described feeling anxious about their child's HbA_{1c} result when they attend clinic, worrying if they have done enough to achieve the target (Lowe et al., 2015). Consequently, parents have reported that their anxiety during clinic appointments about being reprimanded by health professionals about their child's HbA_{1c} level impact on their concentration and ability to take in information during appointments (Lawton et al., 2015b).

The transition to adolescence has also been described as a time of significant stress for many parents. In Marshall and colleagues' study (2009), parents of younger children were already anticipating adolescence to be a stressful period. This could be due to the need to balance their developing independence whilst ensuring their safety. Smaldone and Ritholz (2011) found that the parents in their study had concerns about letting their children have normative experiences of youth. They worried whether the children would still be able to exercise caution when carrying out these activities.

Also, for some parents, there is additional stress due to the financial burden involved with caring for a child with Type 1 diabetes. Financial pressures in dealing with diabetes management, including expenses of medicines and healthy foods, have been reported (Edmonds-Myles, Tamborlane, & Grey, 2010). The costs associated with the treatment impacted on other aspects of their lives (Oskouie, Mehrdad, & Ebrahimi, 2013). These findings demonstrate that the stress of living with a child with Type 1

diabetes includes both aspects that are inherent to the condition as well as the personal and social environment in which the family live. They also indicate that stress and worry have a developmental aspect, and can sometimes create tensions between safety and independence for the child.

One qualitative study examined the experiences of parents caring for a child with Type 1 diabetes in New Zealand (Symons, 2013). This study involved analysis of six semi-structured interviews with parents who had a child with Type 1 diabetes, aged between 4 and 14 years. The nine participants were all New Zealand European. They described how Type 1 diabetes caused significant disruptions to family life, due to the intrusiveness and lack of spontaneity resulting from illness management. Parents also described emotional reactions such as grief, loss, and isolation, and the impact on family relationships. Adaptation was described as coming to terms with a 'new normal', however, parents expressed a continuing burden associated with the demands of caregiving. These findings are consistent with those of international research (e.g., Lowes et al., 2004; Marshall et al., 2009), where the majority of participants were also European. These findings further highlight the psychosocial impact on the family system from a diagnosis of Type 1 diabetes in a child.

The set of responses described above present important implications for health professionals and support people in understanding the psychosocial implications of the caregiving role on parents looking after a child with Type 1 diabetes. This understanding is crucial in providing better care and support for the children diagnosed and for the entire family, at critical times, which will assist in the overall adjustment to the illness. Parents' accounts regarding adjustment indicate that they view it as an on-going and dynamic process where they are continuously adjusting and adapting to the challenges presented by the illness. Parents described not being able to see an endpoint to the process of adjusting and adapting, even though they felt successful in their attempts (Lowes et al., 2005). The process of adjustment for the parents involved a psychosocial transition whereby parents were faced with rebuilding a new model of their world, after being faced with the life-changing event. This dynamic process of adjustment and adaptation is facilitated by a wide array of resources.

Sources of Support for Parents

Parents use various supports in adapting to their demanding caregiving role. They access the help of family, friends, other parents with children with diabetes, and health professionals. Family and friends can often become important sources of support after initially hesitating due to their own fears and emotional responses (Whittemore et al.,

2012). Parents identify the diabetes team as crucial resource, for example, by being available for phone consultations and problem-solving (Sullivan-Bolyai et al., 2003). However, some parents expressed a need for more emotional support from the health care team, especially during the diagnostic period (Buckloh et al., 2008). Support groups have also been described as helpful by parents (Sullivan-Bolyai et al., 2003). They provide parents with the opportunity to meet other parents of children with diabetes, which help normalise and validate their experiences. Parent mentors were found to be a helpful support system for parents of children newly diagnosed with Type 1 diabetes by providing emotional support and identifying available community resources (Sullivan-Bolyai & Lee, 2011).

The strategy of teamwork has been described as an important aspect in the family management of Type 1 diabetes. Parents describe how working together as a team helps with managing the complex demands of the disease. Co-parenting or tag-teaming has been described to emphasise the importance of establishing partnerships in care (Sullivan-Bolyai, Rosenberg, & Bayard, 2006). By being able to work together as a team, parents find mutual support in carrying out the tasks and decision-making involved in managing the disease. Sharing diabetes care responsibilities with partners facilitated the adjustment process and helped to lessen the burden of sole responsibility for the child's welfare (Smaldone & Ritholz, 2011).

In addition to external sources of support, several studies have discussed internal sources of support. Families gain strength through spirituality and religion in coming to accept the disease (de Oliveira, Nascif-Júnior, & Rocha, 2010). Optimism and maintaining a positive attitude has been described as helpful. Feeling optimistic about developments in treatments and the possibility of a future cure can help balance parents' fears (Lowes et al., 2005). Similarly, families sometimes use humor in helping them deal with the situation (Edmonds-Myles et al., 2010). These sources of support demonstrate the variety of internal resources families are able to tap into in their adjustment to the illness, thus making a smoother transition.

The findings described above indicate some of the ways that parents of children with Type 1 diabetes cope with the significant demands of caring for their child. Further qualitative research on parental experiences of caring for a child with Type 1 diabetes can help develop a deeper understanding of how parents adjust to and cope with this demanding illness.

A Critical Review of the Psychological Literature on Resilience

The Concept of Resilience

The current study adopted a resilience perspective to explore the parental experiences of caring for a child with Type 1 diabetes. This perspective formed the conceptual basis to explore how parents cope with the challenges involved in their caregiving role. Resilience and coping have been concepts often used interchangeably in the literature (Fletcher & Sarkar, 2013). The term resilience originates from the Latin word “resilire”, which means “to spring back”. The focus on resilience comes from a salutogenic orientation, which emphasises healthy functioning over pathology (Antonovsky, 1996). There are several definitions of resilience proposed in the psychological literature, demonstrating the definitional ambiguities of this complex concept. Despite this, resilience is generally defined as positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). Within this literature, two conditions are considered central to this concept: the presence of a significant adversity and the achievement of a positive outcome (Masten, 2001). In the context of the current research, adversity refers to living with a child with a chronic illness, Type 1 diabetes in this case. There is a lack of research exploring the experiences and understandings of resilience described by parents in this context. The current research aimed to address this gap through an analysis of parental accounts of their caregiving experiences.

Resilience research has proliferated in the last three decades with a view to understand what helps individuals and families adapt to adversity. Early seminal research on resilience was focused on identifying characteristics of individuals who appeared to function well despite adversity (Garmezy, 1991; Rutter, 1987; Werner & Smith, 1992). Much of this early research was conducted with children and young people, particularly those thought to be at risk for developing psychosocial difficulties (Aranda, Zeeman, Scholes, & Morales, 2012). The Kauai Longitudinal Study was a pioneering research study that examined the impact of adverse life circumstances such as poverty and parental mental illness on the development of a cohort of children born in 1955 in Hawaii, over a period of 40 years (Werner & Smith, 1992). This study identified several personal characteristics such as being robust, socially responsible, adaptable, achievement-oriented, and having good self-esteem, as some of the resilient qualities that helped the young people thrive despite their high-risk environments (Richardson, 2002). As a result of this focus on individual characteristics, resilience became portrayed as an intra-psychic construct (Ungar et al., 2007).

There are several criticisms of this static and internal understanding of resilience. The expectation that special qualities are needed to overcome adversity implies ordinary

adaptive processes are insufficient (Masten, 2001). In addition, this intra-psychic approach potentially ignores the possibility that resilience could be a social phenomenon (Lenette, Brough, & Cox, 2012). The social dimension of resilience as occurring within the person-environment demonstrates resilience as an ongoing process achieved over time and according to contexts rather than as an atypical static inner trait (Lenette et al., 2012). In addition, the idea that resilience emerges from ordinary processes provides a more optimistic outlook than the idea that resilience involves extraordinary and rare processes (Masten, 2001).

These sorts of criticisms led to resilience research shifting its focus from individual and innate attributes to ecological understandings of resilience (Aranda et al., 2012). An ecological perspective advances the idea of resilience as a result of individuals' embeddedness in complex and dynamic social contexts (Harvey, 2007). Richardson (2002, p.308) defined resilience as "the process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors". However, this process conceptualisation of resilience paved way to mainly quantitative research attempting to identify causal relationships between risk and protective factors and transactional processes thought to enhance resilience (Hatala, Waldram, & Crossley, 2013). For example, in the area of disability and chronic conditions of childhood, studies examining parental resilience have tended to use predetermined indicators of resilience and attempted to identify individual attributes that determined health outcomes (Bitsika, Sharpley, & Bell, 2013; Gerstein, Crnic, Blacher, & Baker, 2009; Gudmundsdottir, Schirren, & Boman, 2011). In this conceptualisation, resilience is still 'found' mainly within individuals as an a priori psychological state, even if it originates from repeated interactions between a person and their environment (Aranda et al., 2012). This mainstream perspective also contributes to the false dichotomy of resilient and non-resilient, where resilience is judged on arbitrary assumptions about what is considered a positive or negative outcome (Ungar, 2003). Although the concept of resilience was originally applauded for its salutogenic approach, this dichotomy perpetuates a pathological discourse and undermines the efforts of individuals living through adversity.

As opposed to the notion that resilience is something that is 'found' within individuals, an alternative account of resilience is that resilience is something that is 'made' (Aranda et al., 2012). Ungar (2008) provided the following definition of resilience from this approach:

"In the context of exposure to significant adversity, whether psychological, environmental, or both, resilience is both the capacity of individuals to navigate

their way to health-sustaining resources, including opportunities to experience feelings of wellbeing, and a condition of the individual's family, community and culture to provide these health resources and experiences in culturally meaningful ways" (Ungar, 2008, p.225).

This definition emphasises how resilience is culturally and socially produced (Aranda et al., 2012). Bottrell (2009) asserts that cultural practices, social processes, social change and the nature of individual-social interactions are significant aspects in analysing the concept of resilience. Research supported by this view has emphasised a non-systemic, non-hierarchical relationship between risk and protective factors, and highlights the chaotic, complex, relative, and contextual relationships within these factors among cultures and diverse social and political settings (Ungar, 2004). The Resilience Research Centre at Dalhousie University has studied resilience among children, youth, and families on six continents, using culturally and contextually sensitive ways (Ungar, 2012). This research has examined social and cultural contexts where resilience occur and described how resilience of individuals growing up in challenging situations and environments depend on their social and physical contexts much more than their personal qualities. The findings highlight the multidimensionality of resilience, and how it is negotiated between individuals and their communities (Ungar, 2008). Hence, this view explicitly embraces diversity in the way resilience is nurtured and maintained (Ungar, 2004).

Resilience in the context of caring for a child with Type 1 diabetes is an underexplored area. The only previous study that focused on parental resilience in childhood diabetes investigated the relationship between hope and parental distress, where hope was conceptualised as a resilience factor (Mednick et al., 2007). Such research based on the ecological model fails to accommodate the multitude of meanings that individuals attribute to resilience (Ungar, 2004). A qualitative approach to studying resilience provides the scope to explore potential differences in individuals' perception of the concept and their lived experiences of the phenomenon. It provides an opportunity to develop understandings of resilience that go beyond restrictive traditional definitions, while taking into account the social and cultural context in which resilience occurs (Anderson, 2010; Ungar & Liebenberg, 2005). In the current study, the definition provided by Ungar (2008) was used to explore the concept of resilience within the context of parents caring for a child with Type 1 diabetes.

Family Resilience

Parenting a child with a chronic illness can present many challenges. A child's illness or disability place physical, economic, social, and emotional demands on the family, challenging the family resources (Friesen & Brennen, 2005). Family provide a wider context for understanding the experiences of parents. For this reason, the family resilience literature is instructive for providing a broader understanding of parents' experiences. The concept of family resilience is an attempt to apply the notion of resilience at the level of the family to understand how families successfully engage with stressful circumstances (Kalil, 2003). The family resilience literature aims to go beyond parents to view the family as a single unit with shared goals and values (Hill, Stafford, Seaman, Ross, & Daniel, 2007). It considers the family as being a distinct structure with different characteristics that are more than a sum of the individual members that make up a family. For example, Patterson (2002) describes that a family system is comprised of the individuals within it and the patterns of relationships between them. In spite of this, the family resilience literature relies heavily on the perceptions and behaviours of parents (Hill et al., 2007), demonstrating that it may consider parents as a large part of the family and regard them as representatives or speakers of the family.

There is a considerable amount of literature on the concept of family resilience, aiming to establish it as a separate entity from individual resilience. Walsh (2006) defined family resilience as the coping and adaptational processes in the family as a functional unit. Some descriptions of family resilience also refer to the positive outcomes for the family from enduring adversity. For example, Rolland and Walsh (2006) described family resilience as the ability of a family to withstand and rebound from challenging life events, becoming strengthened and more resourceful as a result. Resilience is seen as involving more than just surviving a crisis; recovery and positive growth is also seen as an outcome (Walsh, 2016). It has also been viewed as not simply being the sum of resilient characteristics of individual family members but rather characteristics of the family unit as a whole (Simon, Murphy, & Smith, 2005).

Walsh (1998, 2003, 2006) proposed the Family Resilience Framework to conceptualise family resilience. The framework covers three areas; family belief systems, organisational patterns and communication processes. Walsh (1998) conceptualised family belief systems to include values, convictions, attitudes, biases and assumptions, and viewed it as the 'heart and soul' of resilience (p.45). Shared beliefs that help the family make sense of crisis situations, maintain a positive outlook and offer spiritual values and purpose are thought to foster family resilience (Walsh, 2002).

Organisational patterns encompass how resilience is enhanced through flexibility, connectedness, and social and economic resources (Walsh, 1998). Flexibility refers to the family's capacity to rebound, reorganise, and adapt to challenges over time (Walsh, 2002). Family cohesion, the emotional and structural bonding within family members, is seen to play an important role. Social and economic resources are suggested as fostering family resilience through the support of extended kin, social and community networks (Walsh, 2006). Communication processes include clarity of communication between family members, empathic emotional sharing which builds a climate of mutual trust, and problem-solving strategies that follow a smooth path from clear communication, decision-making to action (Walsh, 1998, 2006). These key processes emphasise particular qualities of families and ways of interactions between family members, which are thought to produce good outcomes.

McCubbin and McCubbin (1993) developed the Resiliency Model of Family Stress, Adjustment and Adaptation to conceptualise family resilience. The model depicts two phases, an adjustment phase and an adaptation phase that a family goes through after experiencing a stressful life event. Resilience is described as a process within this adjustment and adaptation (Coyle, 2011). In the adjustment phase, the family counts on established patterns of family functioning and protective factors to cope with the situation. According to McCubbin and colleagues (1997), some of the family protective factors include family celebrations, family hardiness, family time and routines and family traditions. If these are not enough, the family is seen to be in a crisis state and moves into the adaptation phase. In the adaptation phase, family and illness demands are seen to increase family vulnerability, causing strength and resilience factors to be activated. Processes that enable good outcomes in this phase are referred to as recovery factors. A number of general resilience factors (both protective and recovery) have been outlined by McCubbin and colleagues (1997). These include family problem-solving communication, equality, spirituality, flexibility, truthfulness, hope, family hardiness, family time and routines, social support and health. A cluster of four family recovery factors have been described by McCubbin and colleagues (1997) in the context of the long-term care of a child with a chronic illness; family integration; family support and esteem building; family recreation orientation, control and organisation; and family optimism and mastery. These characteristics are considered to play important roles in a family's adjustment to a chronic illness in a child.

The family resilience approach has been used in several studies examining family responses to chronic conditions of childhood. Family resilience has been studied within childhood cancer (Brody & Simmons, 2007; Lee et al., 2004; McCubbin, Balling, Possin, Friedrich, & Bryne, 2002), autism (Bayat, 2007; Plumb, 2011) and childhood diabetes

(Coetzee, 2007; Koegelenberg, 2013). Most of these studies were guided by the theoretical models described earlier, which determined the ways that family experiences were understood and described. For example, McCubbin and colleagues (2002) used the Resiliency Model of Family Stress, Adjustment, and Adaptation and described six factors that reflected aspects of family resilience for parents of children diagnosed with cancer; internal family strengths of rapid mobilization and reorganisation; support from the health care team; support from the extended family; support from the community; support from workplace; and changes in family appraisal. Similarly, Brody and Simmons (2007) used the same model to study family resilience in fathers of children diagnosed with cancer. They described four major themes; changes and adjustment in family life, communication patterns, social support, and the resultant effect on fathers. Interestingly, Lee and colleagues (2004) proposed 21 attributes that underpinned family resilience within families with a child diagnosed with cancer, including family characteristics such as positive outlook, adaptability and communication, which were still consistent with the existing models.

Furthermore, Plumb (2011) used Walsh's family resilience framework to investigate the impact of social support and family resilience on parenting stress in families with a child with autism. The study reported that greater family resilience was associated with lower levels of stress. Similarly, Bayat (2007) used the same framework and described themes consistent with the framework, such as making positive meaning out of adversity. However, the author noted there were positive aspects of the parental experience that did not fit within the framework and were therefore unexplored, such as parents becoming advocates for their children or parenting as a source of pride and honour. This indicates that important elements of the parents' experience can be missed by adhering closely to such models.

Two studies have examined family resilience in the context of childhood diabetes (Coetzee, 2007; Koegelenberg, 2013). These studies were underpinned by the Resiliency Model of Family Stress, Adjustment, and Adaptation and used a mixed-methods approach. Family resilience was conceptualised as a reflection of the parents' endorsement on items assessing family characteristics such as hardiness or communication. The qualitative component of these studies involved content analysis of answers to one open-ended question about parents' opinion on factors that helped with family adjustment after the diagnosis of Type 1 diabetes in their child. The findings described resources within and outside the family. Parents' acceptance of the condition through treating everyone equally and taking time out from diabetes related activities was described as a main source that helped the families. Spirituality, religious beliefs and prayer were also highlighted as helpful for parents in finding meaning in

their challenge. Parents also described the helpful aspect of acquiring skills and knowledge related to Type 1 diabetes in advancing their understanding of the illness. A supportive family unit and parents working together as a team was also described as contributing to positive adjustment to the illness. Open communication between family members was also emphasised as helpful in solving illness-related problems. Resources external to the family, such as social support through emotional and instrumental means, from extended family, friends, and health professionals were also highlighted. While these qualitative findings give a flavour of what parents found helpful, they do not describe the in-depth lived experiences of caring for a child with Type 1 diabetes.

As a whole, the findings of these studies of family resilience attempt to highlight particular qualities of families such family beliefs, communication between family members, cohesiveness, responsiveness to stress, and support from others as important indicators of family resilience. These findings indicate how parents perceived these qualities as important to their family's successful coping with difficult situations. These indicate the ways that parental experiences are nestled within a wider family context. These findings also demonstrate the limitations of an internal understanding of resilience as with the mainstream individual resilience literature. These understandings of resilience limit the ways that individuals describe their varied understandings of the concept and suppresses accounts of resilience that are embedded within the daily lived experiences of family members. Families can cope in unique ways, and utilise unique resources. Applying a standard view of how people cope can place limitations on how well individual experiences are understood.

Furthermore, the focus on the family as a unit in this literature may mask differences in wellbeing among the different family members, such that individual interests, differences, and tensions are missed (Hill et al., 2007). Consequently, important parental experiences and significant differences within a family due to gendered experiences of caregiving or employment may be overlooked. Negative experiences described by parents that do not feature in the descriptions of family resilience may also be ignored. Negative aspects of caring such as social isolation and increased stress can be missed by a focus on processes that are thought to contribute to positive outcomes.

In summary, the family resilience literature points to the difficulties in trying to locate resilience within families. In particular, the family resilience literature has not taken into account the varied meanings that parents attribute to their experiences of caring for a child with a chronic condition and the importance of context when understanding

their experiences. Complex socio-environmental factors such as the caregivers' access to social, financial, and material resources can shape this context (Giesbrecht, Wolse, Crooks, & Stajduhar, 2015). Multiple meanings of concepts such as spirituality and coping can exist for these parents, which are not explored from such perspectives. Understanding parental experiences within the wider social and cultural context would be important in considering how they come to cope with the challenges of a chronic condition of childhood.

Current Study

In light of the increasing prevalence of childhood diabetes worldwide (IDF, 2015) and the central role that parents play in children's diabetes care, the current study aims to add to the growing body of qualitative literature on parental experiences within childhood diabetes. Further research on what it is like to be a parent of a child with Type 1 diabetes will help make sense of the meaning of childhood diabetes from the perspective of the parents. This can provide an insight into the processes of coping with and adapting to the challenges involved in the caregiving experience. The current study employed the qualitative approach of Interpretative Phenomenological Analysis (IPA) to explore the lived experiences of parents in more depth.

A particular aim of the current study was to explore parental resilience, to provide an insight into the ways that parents cope with their demanding caregiving role. A qualitative approach to studying resilience allows thick descriptions of the phenomenon in very specific contexts, providing the opportunity to discover unnamed processes and reveal novel aspects of resilience and thriving (Massey, Cameron, Ouellette, & Fine, 1998; Ungar, 2003). This methodological approach allows for an in-depth exploration of the processes of coping within the context of caring for a child with Type 1 diabetes, and the potential to contribute to new knowledge as a result.

References

- Åkerblom, H. K., Vaarala, O., Hyöti, H., Ilonen, J., & Knip, M. (2002). Environmental factors in the etiology of Type 1 diabetes. *American Journal of Medical Genetics, 115*, 18-29. doi:10.1002/ajmg.10340
- Allen, P. J. (2010). The primary care provider and children with chronic conditions. In P. J. Allen, J. A. Vessey & N. A. Schapiro (Eds.), *Primary care of the child with a chronic condition* (5th ed., pp. 3-21). Missouri: Elsevier Inc.
- Ambler, G. & Cameron, F. (Ed.). (2010). *Caring for diabetes in children and adolescents* (3rd ed.). Australia: Blue Star Print Group.
- American Diabetes Association. (2014). Diabetes care in the school and day care setting. *Diabetes Care, 37*(1), 91-96. doi:10.2337/dc14-S091
- American Diabetes Association. (2015). Children and adolescents. *Diabetes Care, 38*(1), 70-76. doi:10.2337/dc15-S014
- Anderson, K. M. (2010). *Resilience in survivors of family violence*. New York, NY: Springer Publishing Company.
- Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11-18. doi:10.1093/heapro/11.1.11
- Aranda, K., Zeeman, L., Scholes, J., & Morales, A. S-M. (2012). The resilient subject: Exploring subjectivity, identity and the body in narratives of resilience. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 16*(5), 548-563. doi:10.1177/1363459312438564
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet, 383*(9911), 69-82. doi:10.1016/S0140-6736(13)60591-7
- Barlow, J. H., & Ellard, D. R. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of research evidence base. *Child: Care, Health & Development, 32*(1), 19-31. doi:10.1111/j.1365-2214.2006.00591.x
- Barlow, S. E. (2007). Expert committee recommendations regarding the prevention, assessment, and treatment of child and adolescent overweight and obesity: Summary report. *Pediatrics, 120*(4), 164-192. doi:10.1542/peds.2007-2329C
- Barnard, K., Thomas, S., Noyes, K., & Waugh, N. (2010). Fear of hypoglycaemia in parents of young children with type 1 diabetes: A systematic review. *BMC Pediatrics, 10*(50), 1-8. doi:10.1186/1471-2431-10-50

- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714. doi:10.1111/j.1365-2788.2007.00960.x
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 25(5), 533-543. doi:10.1007/s10882-013-9333-5
- Bottrell, D. (2009). Understanding 'marginal' perspectives: Towards a social theory of resilience. *Qualitative Social Work*, 8(3), 321-339. doi:10.1177/1473325009337840
- Bowes, S., Lowes, S., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with Type 1 diabetes. *Journal of Advanced Nursing*, 65(5), 992-1000. doi:10.1111/j.1365-2648.2009.04963.x
- Branstetter, J. E., Domian, E. W., Williams, P. D., Graff, J. C., & Piamjariyakul, U. (2008). Communication themes in families of children with chronic conditions. *Issues in Comprehensive Pediatric Nursing*, 31(4), 171-184. doi:10.1080/01460860802475184
- Brody, A. C., & Simmons, L. A. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing*, 24(3), 152-165. doi:10.1177/1043454206298844
- Browning, C., Schlomann, P., & Schmitke, J. (2012). Chronic conditions. In N. L. Potts & B. L. Mandleco (Eds.), *Pediatric nursing: Caring for children and their families* (3rd ed., pp. 555-580). Clifton Park, NY: Delmar Cengage Learning.
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, J. A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth. *Diabetes Care*, 31(8), 1516-1520. doi:10.2337/dc07-2349
- Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics*, 117(1), 48-60. doi:10.1542/peds.2005-0789
- Cashin, G. H., Small, S. P., & Solberg, S. M. (2008). The lived experience of fathers who have children with asthma: A phenomenological study. *Journal of Pediatric Nursing*, 23(5), 372-385. doi:10.1016/j.pedn.2007.08.001

- Chaplin, J. E., Hanas, R., Lind, A., Tollig, H., Wramner, N., & Lindblad, B. (2009). Assessment of childhood diabetes-related quality-of-life in West Sweden. *Acta Paediatrica*, *98*(2), 361-366. doi:10.1111/j.1651-2227.2008.01066.x
- Christian, B. J. (2010). Research commentary- Challenges for parents and families: Demands of caregiving of children with chronic conditions. *Journal of Pediatric Nursing*, *25*, 299-301. doi:10.1016/j.pedn.2010.04.008
- Coetzee, M. (2007). *Resilience in families living with a type 1 diabetic child*. (Unpublished master's thesis). Nelson Mandela Metropolitan University, Port Elizabeth, South Africa.
- Coffey, J. S. (2006). Parenting a child with chronic illness: A metasynthesis. *Pediatric Nursing*, *32*(1), 51-59.
- Cohen, D. M., Lumley, M. A., Naar-King, S., Partridge, T., & Cakan, N. (2004). Child behavior problems and family functioning as predictors of adherence and glycemic control in economically disadvantaged children with Type 1 diabetes: A prospective study. *Journal of Pediatric Psychology*, *29*(3), 171-184. doi:10.1093/jpepsy/jsh019
- Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, *38*(8), 809-828. doi:10.1093/jpepsy/jst049
- Coyle, J. P. (2011). Resilient families help make resilient children. *Journal of Family Strengths*, *11*(1), 1-16.
- de Boer, I. H., Rue, T. C., Cleary, P. A., Lachin, J. M., Molitch, M. E., Steffes, M. W., . . . Brunzell, J. D. (2011). Long-term renal outcomes of patients with Type 1 diabetes mellitus and microalbuminuria: An analysis of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications cohort. *Archives of Internal Medicine*, *171*(5), 412-420. doi:10.1001/archinternmed.2011.16
- de Oliveira, I. R., Nascif-Júnior, I. A., & Rocha, S. M. M. (2010). Promoting health in families of children with Type 1 diabetes mellitus. *International Journal of Nursing Practice*, *16*, 106-111. doi:10.1111/j.1440-172X.2009.01806.x
- Derraik, J. G. B., Reed, P. W., Jefferies, C., Cutfield, S. W., Hofman, W., & Cutfield, W. (2012). Increasing incidence and age at diagnosis among children with Type 1 diabetes mellitus over a 20-year period in Auckland (New Zealand). *PLoS ONE*, *7*(2), 1-4, doi:10.1371/journal.pone.0032640

- Diabetes Youth New Zealand. (n.d.). *About diabetes*. Retrieved June 1, 2017, from <http://www.diabetesyouth.org.nz/about-diabetes/>
- DIAMOND Research Group. (2006). Incidence and trends of childhood Type 1 diabetes worldwide 1990–1999. *Diabetic Medicine*, *23*(8), 857-866. doi:10.1111/j.1464-5491.2006.01925.x
- Dickinson, A. R., Smythe, E., & Spence, D. (2006). Within the web: The family-practitioner relationship in the context of chronic childhood illness. *Journal of Child Health Care*, *10*(4), 309-325. doi:10.1177/1367493506067883
- Dodgson, J. E., Garwick, A., Blozis, S. A., Patterson, J. M., Bennett, F. C., & Blum, R. W. (2000). Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*, *6*(3), 252. doi:10.1177/107484070000600304
- Doyle, E. A., & Grey, M. (2010). Diabetes mellitus (types 1 and 2). In P. J. Allen, J. A. Vessey & N. A. Schapiro (Eds.), *Primary care of the child with a chronic condition* (5th ed.). St. Louis, Missouri: Mosby Elsevier.
- Driscoll, K. A., Johnson, S. B., Barker, D., Quittner, A. L., Deeb, L. C., Geller, D. E., . . . Silverstein, J. H. (2010). Risk factors associated with depressive symptoms in caregivers of children with Type 1 diabetes or cystic fibrosis. *Journal of Pediatric Psychology*, *35*(8), 814-822. doi:10.1093/jpepsy/jsp138
- Driscoll, K. A., Raymond, J., Naranjo, D., Patton, S. R. (2016). Fear of hypoglycemia in children and adolescents and their parents with Type 1 diabetes. *Current Diabetes Reports*, *16*(8), 1-9. doi:10.1007/s11892-016-0762-2
- Edmonds-Myles, S., Tamborlane, W. V., & Grey, M. (2010). Perception of the impact of Type 1 diabetes on low-income families. *The Diabetes Educator*, *36*, 318-325. doi:10.1177/0145721709349219
- Eiselein, L., Schwartz, H. J., & Rutledge, J. C. (2004). The challenge of Type 1 diabetes mellitus. *ILAR Journal*, *45*(3), 231-236. doi:10.1093/ilar.45.3.231
- Falvo, D. R. (2009). Endocrine conditions. *Medical and psychosocial aspects of chronic illness and disability* (4th ed., pp. 333-351). Sudbury, MA: Jones and Bartlett Publishers.
- Fletcher, D., & Sarkar, M. (2013). Psychological resilience: A review and critique of definitions, concepts, and theory. *European Psychologist*, *18*(1), 12-23. doi:10.1027/1016-9040/a000124

- Friesen, B., & Brennan, E. (2005). Strengthening families and communities: System building for resilience. In M. Ungar (Ed.), *Handbook for working with children and youth: Pathways to resilience across cultures and contexts* (pp. 295-312). Thousand Oaks: SAGE Publications.
- Gannoni, A. F., & Shute, R. H. (2009). Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry, 15*(1), 39-53. doi:10.1177/1359104509338432
- Garnezy, N. (1991). Resiliency and vulnerability to adverse developmental outcomes associated with poverty. *American Behavioral Scientist, 34*(4), 416-430. doi:10.1177/0002764291034004003
- George, A., Vickers, M. H., Wilkes, L., & Barton, B. (2008). Working and caring for a child with chronic illness: Challenges in maintaining employment. *Employee Responsibilities and Rights Journal, 20*(3), 165-176. doi:10.1007/s10672-008-9065-3
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997. doi:10.1111/j.1365-2788.2009.01220.x
- Giesbrecht, M., Wolse, F., Crooks, V. A., & Stajduhar, K. (2015). Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: A qualitative case study. *Palliative & Supportive Care, 13*(03), 555-565. doi:10.1017/S1478951513001028
- Goodman, S. (2012). Endocrine alterations. In N. L. Potts & B. L. Mandleco (Eds.), *Pediatric nursing: Caring for children and their families* (3rd ed., pp. 983-1022). Clifton Park, NY: Delmar Cengage Learning.
- Grey, M., Jaser, S. S., Whittemore, R., Jeon, S., & Lindemann, E. (2011). *Nursing Research, 60*(3), 173-181. doi:10.1097/NNR.0b013e3182159c8f.
- Gudmundsdottir, E., Schirren, M., & Boman, K. K. (2011). Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer. *Acta Oncologica, 50*(3), 373-380. doi:10.3109/0284186X.2010.489572
- Harper, F. W. K., Peterson, A. M., Albrecht, T. L., Taub, J. W., Phipps, S., & Penner, L. A. (2014). Posttraumatic stress symptoms in parents of pediatric cancer patients: A mediational analysis. *Journal of Traumatic Stress Disorders & Treatment, 3*(4), 1000133. doi:10.4172/2324-8947.1000133

- Harvey, M. R. (2007). Towards an ecological understanding of resilience in trauma survivors. *Journal of Aggression, Maltreatment & Trauma, 14*(1-2), 9-32. doi:10.1300/J146v14n01_02
- Hatala, A. R., Waldram, J. B., & Crossley, M. (2013). Doing resilience with "half a brain:" Navigating moral sensibilities 35 years after hemispherectomy. *Culture, Medicine and Psychiatry, 37*(1), 148-178. doi:10.1007/s11013-012-9294-7
- Hatton, D. L., Canam, C., Thorne, S., & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing, 22*(3), 569-577. doi:10.1046/j.1365-2648.1995.22030569.x
- Haugstvedt, A., Wentzel-Larsen, T., Graue, M., Sjøvik, O., & Rokne, B. (2010). Fear of hypoglycaemia in mothers and fathers of children with Type 1 diabetes is associated with poor glycaemic control and parental emotional distress: A population-based study. *Diabetic Medicine, 27*(1), 72-78. doi:10.1111/j.1464-5491.2009.02867.x
- Hill, M., Stafford, A., Seaman, P., Ross, N., & Daniel, B. (2007). *Parenting and resilience*. York: Joseph Rowntree Foundation.
- Hilliard, M. E., Monaghan, M., Cogen, F. R., & Streisand, R. (2011). Parent stress and child behaviour among young children with type 1 diabetes. *Child: Care, Health and Development, 37*(2), 224-232. doi:10.1111/j.1365-2214.2010.01162.x
- Hummelinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling, 62*(2), 228-234. doi:10.1016/j.pec.2005.07.006
- International Diabetes Federation. (2015). *IDF Diabetes Atlas* (7th ed.). Brussels, Belgium: International Diabetes Federation.
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. (2008). Mediators of depressive symptoms in children with Type 1 Diabetes and their mothers. *Journal of Pediatric Psychology, 33*(5), 509-519. doi:10.1093/jpepsy/jsm104
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. (2009). Coping and psychosocial adjustment in mothers of young children with Type 1 diabetes. *Children's Health Care, 38*(2), 91-106. doi:10.1080/02739610902813229
- Jefferies, C., Owens, N., & Wiltshire, E. (2015). Care for children and adolescents with diabetes in New Zealand District Health Boards: Is the clinical resourcing ready for the challenge? *New Zealand Medical Journal, 128*(1424), 20-27.

- Jensen, M. M., & Kazak, A. E. (2004). Pediatric psychology. In C. Spielberger (Ed.), *Encyclopedia of Applied Psychology* (Vol. 2, pp. 821-825). Tampa, Florida: Elsevier Inc.
- Johnson, S. R., Cooper, M. N., Jones, T. W., & Davis, E. A. (2013). Long-term outcome of insulin pump therapy in children with Type 1 diabetes assessed in a large population-based case-control study. *Diabetologia*, *56*, 2392-2400.
- Jönsson, L., Lundqvist, P., Tiberg, I., & Hallström, I. (2015). Type 1 diabetes- Impact on children and parents at diagnosis and 1 year subsequent to the child's diagnosis. *Scandinavian Journal of Caring Sciences*, *29*(1), 126-135. doi:10.1111/scs.12140
- Kalil, A. (2003). *Family resilience and good child outcomes: A review of the literature*. Wellington, New Zealand: Ministry of Social Development.
- Kepreotes, E., Keatinge, D., & Stone, T. (2010). The experience of parenting children with chronic health conditions: A new reality. *Journal of Nursing and Healthcare of Chronic Illness*, *2*(1), 51-62. doi:10.1111/j.1752-9824.2010.01047.x
- Koegelenberg, G. J. (2013). *Resilience characteristics of families with a child with Type 1 diabetes*. (Unpublished master's thesis). Stellenbosch University, Stellenbosch, South Africa.
- Lawton, J., Waugh, N., Barnard, K. D., Noyes, K., Harden, J., Stephen, J., . . . Rankin, D. (2015a). Challenges of optimising glycaemic control in children with Type 1 diabetes: A qualitative study of parents' experiences and views. *Diabetic Medicine*, *32*, 1063-1070. doi:10.1111/dme.12660
- Lawton, J., Waugh, N., Noyes, K., Barnard, K., Harden, J., Bath, L., . . . Rankin, D. (2015b). Improving communication and recall of information in paediatric diabetes consultations: A qualitative study of parents' experiences and views. *BMC Pediatrics*, *15*, 1-9. doi:10.1186/s12887-015-0388-6
- Lee, I., Lee, E., Kim, H. S., Park, Y. S., Song, M., & Park, Y. H. (2004). Concept development of family resilience: A study of Korean families with a chronically ill child. *Journal of Clinical Nursing*, *13*, 636-645. doi:10.1111/j.1365-2702.2004.00845.x
- Lenette, C., Brough, M., & Cox, L. (2012). Everyday resilience: Narratives of single refugee women with children. *Qualitative Social Work*, *12*, 637-653. doi:10.1177/1473325012449684
- Lindström, C., Åman, J., & Norberg, A. L. (2011). Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease

- duration and glycaemic control in children with Type 1 diabetes mellitus. *Acta Paediatrica*, *100*(7), 1011-1017. doi:10.1111/j.1651-2227.2011.02198.x
- Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., & Gregory, J. W. (2015). The experience of living with Type 1 diabetes and attending clinic from the perception of children, adolescents and carers: Analysis of qualitative data from the DEPICTED Study. *Journal of Pediatric Nursing*, *30*, 54-62. doi:10.1016/j.pedn.2014.09.006
- Lowes, L., Gregory, J. W., & Lyne, P. (2005). Newly diagnosed childhood diabetes: A psychosocial transition for parents? *Journal of Advanced Nursing*, *50*(3), 253-261. doi:10.1111/j.1365-2648.2005.03388.x
- Lowes, L., Lyne, P., & Gregory, J. W. (2004). Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*, *21*(6), 531-538. doi:10.1111/j.1464-5491.2004.01193.x
- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, *71*(3), 543-562. doi:10.1111/1467-8624.00164
- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Epidemiology of type 1 diabetes. *Endocrinology and Metabolism Clinics of North America*, *30*(3), 481-497. doi:10.1016/j.ecl.2010.05.011
- Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with Type 1 diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing*, *18*(12), 1703-1710. doi:10.1111/j.1365-2702.2008.02737.x
- Massey, S., Cameron, A., Ouellette, S., & Fine, M. (1998). Qualitative approaches to the study of thriving: What can be learned? *Journal of Social Issues*, *54*(2), 337-355. doi:10.1111/j.1540-4560.1998.tb01222.x
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, *56*(3), 227-238. doi:10.1037/0003-066X.56.3.227
- McCubbin, H. I., McCubbin, M. A., Thompson, A. I., Han, S., & Allen, C. T. (1997). Families under stress: What makes them resilient. *Journal of Family and Consumer Sciences*, *89*(3), 2-11.
- McCubbin, M. A., & McCubbin, H. I. (1993). Families coping with illness: The Resiliency Model of Family Stress, Adjustment, and Adaptation. In C. B. Danielson, B. Hamel-Bissell & P. Winstead-Fry (Eds.). *Families, health, & illness: Perspectives on coping and intervention* (pp. 21-63). New York: Mosby.

- McCubbin, M., Balling, K., Possin, P., Friedrich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations*, *51*(2), 103-111. doi:10.1111/j.1741-3729.2002.00103.x
- Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with Type 1 diabetes. *Children's Health Care*, *36*(4), 385-396. doi:10.1080/02739610701601403
- Merkel, R. M., & Wright, T. (2012). Parental self-efficacy and online support among parents of children diagnosed with Type 1 diabetes mellitus. *Pediatric Nursing*, *38*(6), 303-308.
- Miller, V. A. (2009). Parent-child collaborative decision making for the management of chronic illness: A qualitative analysis. *Families, Systems, & Health*, *27*(3), 249-266. doi:10.1037/a0017308
- Ministry of Health (2016). Virtual Diabetes Register. <http://www.health.govt.nz/our-work/diseases-and-conditions/diabetes/about-diabetes/virtual-diabetes-register-vdr>. Accessed 15 Feb 2017
- Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviors among parents of young children with Type 1 diabetes: Associations with illness characteristics and parent functioning. *Families, Systems, & Health*, *27*(1), 28-38. doi:10.1037/a0014770
- Monaghan, M., Hilliard, M., Cogen, F., & Streisand, R. (2011). Supporting parents of very young children with type 1 diabetes: Results from a pilot study. *Patient Education and Counseling*, *82*(2), 271-274. doi:10.1016/j.pec.2010.04.007
- Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. C. (2014). Family cohesion and health-related quality of life of children with Type 1 diabetes: The mediating role of parental adjustment. *Journal of Child and Family Studies*, *23*(2), 347-359. doi:10.1007/s10826-013-9758-6
- Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2006). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180-187. doi:10.1111/j.1365-2214.2006.00644.x
- Nathan, D. M., Turgeon, H., & Regan, S. (2007). Relationship between glycated haemoglobin levels and mean glucose levels over time. *Diabetologia*, *50*, 2239-2244, doi:10.1007/s00125-007-0803-0

- National Institute for Health and Care Excellence (NICE). (2015). *Diabetes (type 1 and type 2) in children and young people: Diagnosis and management*. Retrieved from <https://www.nice.org.uk/guidance/ng18/resources/diabetes-type-1-and-type-2-in-children-and-young-people-diagnosis-and-management-1837278149317>
- Nelson, P. A., Kirk, S. A., Caress, A., & Glenny, A. (2012). Parents' emotional and social experiences of caring for a child through cleft treatment. *Qualitative Health Research, 22*(3), 346-359. doi:10.1177/1049732311421178
- Nuutila, L., & Salanterä, S. (2006). Children with a long-term illness: Parents' experiences of care. *Journal of Pediatric Nursing, 21*(2), 153-160. doi:10.1016/j.pedn.2005.07.005
- Oskouie, F., Mehrdad, N., & Ebrahimi, H. (2013). Mediating factors of coping process in parents of children with type 1 diabetes. *Journal of Diabetes and Metabolic Disorders, 12*, 1-7. doi:10.1186/2251-6581-12-20
- Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology, 58*(3), 233-246. doi:10.1002/jclp.10019
- Patton, S. R., Dolan, L. M., Henry, R., & Powers, S. W. (2007). Parental fear of hypoglycemia: Young children treated with continuous subcutaneous insulin infusion. *Pediatric Diabetes, 8*(6), 362-368. doi:10.1111/j.1399-5448.2007.00242.x
- Perrin, J. M., Anderson, E., & Van Cleave, J. (2014). The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. *Health Affairs, 33*(12), 2099-2105. doi:10.1377/hlthaff.2014.0832
- Pickup, J. C., & Sutton, A. J. (2008). Severe hypoglycaemia and glycaemic control in Type 1 diabetes: Meta-analysis of multiple daily insulin injections compared with continuous subcutaneous insulin infusion. *Diabetic Medicine, 25*(7), 765-774. doi:10.1111/j.1464-5491.2008.02486.x
- Plumb, J. C. (2011). *The impact of social support and family resilience on parenting stress in families with a child diagnosed with an autism spectrum disorder*. (Unpublished doctoral dissertation). University of Pennsylvania, Philadelphia.
- Pop-Busui, R., Low, P. A., Waberski, B. H., Martin, C. L., Albers, J. W., Feldman, E. L., . . . Herman, W. H. (2009). Effects of prior intensive insulin therapy on cardiac autonomic nervous system function in Type 1 diabetes mellitus: The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and

- Complications Study (DCCT/EDIC). *Circulation*, 119(22), 2886-2893. doi:10.1161/CIRCULATIONAHA.108.837369
- Quirk, H., Blake, H., Dee, B., & Glazebrook, C. (2014). "You can't just jump on a bike and go": Qualitative study exploring parents' perceptions of physical activity in children with Type 1 diabetes. *BMC Pediatrics*, 14, 1-12. doi:10.1186/s12887-014-0313-4
- Rankin, D., Harden, J., Noyes, K., Waugh, N., Barnard, K., & Lawton, J. (2015). Parents' experiences of managing their child's diabetes using an insulin pump: A qualitative study. *Diabetic Medicine*, 32, 1063-1070. doi:10.1111/dme.12683
- Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K. D., Stephen, J., . . . Lawton, J. (2014a). Pathways to diagnosis: A qualitative study of the experiences and emotional reactions of parents of children diagnosed with Type 1 diabetes. *Pediatric Diabetes*, 15, 591-598. doi:10.1111/pedi.12124
- Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K. D., & Lawton, J. (2014b). Parents' information and support needs when their child is diagnosed with Type 1 diabetes: A qualitative study. *Health Expectations*, 19, 580-591. doi:10.1111/hex.12244
- Rehm, R. S. (2000). Parental encouragement, protection, and advocacy for Mexican-American children with chronic conditions. *Journal of Pediatric Nursing*, 15(2), 89-98. doi:10.1053/jn.2000.5448
- Rehm, R. S., & Bradley, J. F. (2005). The search for social safety and comfort in families raising children with complex chronic conditions. *Journal of Family Nursing*, 11(1), 59-78. doi:10.1177/1074840704272956
- Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, 58(3), 307-321. doi:10.1002/jclp.10020
- Robling, M., McNamara, R., Bennert, K., Butler, C. C., Channon, S., Cohen, D., . . . Gregory, J. W. (2012). The effect of the Talking Diabetes consulting skills intervention on glycaemic control and quality of life in children with type 1 diabetes: Cluster randomised controlled trial (DEPICTED study). *British Medical Journal*, 344, 1-17. doi:10.1136/bmj.e2359
- Rolland, J. S., & Walsh, F. (2006). Facilitating family resilience with childhood illness and disability. *Current Opinion in Pediatrics*, 18(5), 527-538. doi:10.1097/01.mop.0000245354.83454.68

- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57(3), 316-331. doi:10.1111/j.1939-0025.1987.tb03541.x
- Sallfors, C., & Hallberg, L. R. M. (2003). A parental perspective on living with a chronically ill child: A qualitative study. *Families, Systems, & Health*, 21(2), 193-204. doi:10.1037/1091-7527.21.2.193
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., . . . Clark, N. (2005). Care of children and adolescents with Type 1 diabetes. *Diabetes Care*, 28(1), 186-212. doi:10.2337/diacare.28.1.186
- Simon, J. B., Murphy, J. J., & Smith, S. M. (2005). Understanding and fostering family resilience. *The Family Journal*, 13(4), 427-436. doi:10.1177/1066480705278724
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of parenting children with Type 1 diabetes diagnosed early in childhood. *Journal of Pediatric Health Care*, 25(2), 87-95. doi:10.1016/j.pedhc.2009.09.003
- Smith, J., Cheater, F., & Bekker, H. (2015). Parents' experiences of living with a child with a long-term condition: A rapid structured review of the literature. *Health Expectations*, 18(4), 452-474. doi:10.1111/hex.12040
- Soni, A., Agwu, J. C., Wright, N. P., Moudiotis, C., Kershaw, M., Edge, J., . . . Ng, S. M. (2016). Management of children with Type 1 diabetes during illness: A National survey. *Postgraduate Medical Journal*, 92, 447-449. doi:10.1136/postgradmedj-2015-133786
- Sparud-Lundin, C., Hallström, I., & Erlandsson, L. (2013). Challenges, strategies, and gender relations among parents of children recently diagnosed with Type 1 diabetes. *Journal of Family Nursing*, 19, 249-273. doi:10.1177/1074840713484386
- Statistics New Zealand. (2007). *Hot off the press: 2006 disability survey*. Wellington, New Zealand: Statistics New Zealand.
- Streisand, R., Mackey, E. R., & Herge, W. (2010). Associations of parent coping, stress, and well-being in mothers of children with diabetes: Examination of data from a national sample. *Maternal and Child Health Journal*, 14, 612-617. doi:10.1007/s10995-009-0497-7
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing*, 18(1), 21-29. doi:10.1053/jpnd.2003.4

- Sullivan-Bolyai, S., & Lee, M. L. (2011). Parent mentor perspectives on providing social support to empower parents. *The Diabetes Educator*, 37, 35-43. doi:10.1177/0145721710392248
- Sullivan-Bolyai, S., Rosenberg, R., & Bayard, M. (2006). Fathers' reflections on parenting young children with Type 1 diabetes. *The American Journal of Maternal Child Nursing*, 31(1), 24-31.
- Symons, J. M. (2013). *The impact on the family of living with a child with Type 1 diabetes*. (Unpublished master's thesis). Eastern Institute of Technology, Taradale, New Zealand.
- Todd, J. A. (2010). Etiology of Type 1 diabetes. *Immunity*, 32, 457-467. doi:10.1016/j.immuni.2010.04.001
- UK Hypoglycaemia Study Group (2007). Risk of hypoglycaemia in types 1 and 2 diabetes: Effects of treatment modalities and their duration. *Diabetologia*, 50, 1140-1147. doi:10.1007/s00125-007-0599-y
- Ungar, M. (2003). Qualitative contributions to resilience research. *Qualitative Social Work*, 2(1), 85-102.
- Ungar, M. (2004). A constructionist discourse on resilience: Multiple contexts, multiple realities among at-risk children and youth. *Youth & Society*, 35(3), 341-365. doi:10.1177/0044118x03257030
- Ungar, M. (2008). Resilience across cultures. *British Journal of Social Work*, 38, 218-235. doi:10.1093/bjsw/bcl343
- Ungar, M. (Ed.). (2012). *The social ecology of resilience: A handbook of theory and practice*. London: Springer.
- Ungar, M., Brown, M., Liebenberg, L., Othman, R., Kwong, W. M., Armstrong, M., & Gilgun, J. (2007). Unique pathways to resilience across cultures. *Adolescence*, 42(166), 287-310.
- Ungar, M., & Liebenberg, L. (2005). The International Resilience Project: A mixed-methods approach to the study of resilience across cultures. In M. Ungar (Ed.), *Handbook for working with children and youth: Pathways to resilience across cultures and contexts* (pp. 211-226). Thousand Oaks: SAGE Publications.
- Usher-Smith, J., Thompson, M. J., & Sharp, S. J., & Walter, F. M. (2011). Factors associated with the presence of diabetic ketoacidosis at diagnosis of diabetes in children and young adults: A systematic review. *The British Medical Journal*, 343, 1-16. doi:10.1136/bmj.d4092

- Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *JAMA*, *303*(7), 623-630. doi:10.1001/jama.2010.104
- Waite-Jones, J. M., & Madill, A. (2008). Concealed concern: Fathers' experiences of having a child with Juvenile Idiopathic Arthritis. *Psychology & Health*, *23*(5), 585-601. doi:10.1080/08870440802036911
- Walsh, F. (1998). *Strengthening family resilience*. New York: Guilford Press.
- Walsh, F. (2002). A family resilience framework: Innovative practice applications. *Family Relations*, *51*, 130-137.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, *42*(1), 1-18.
- Walsh, F. (2006). *Strengthening family resilience* (2nd ed.). New York: Guilford Press.
- Walsh, F. (2016). *Strengthening family resilience* (3rd ed.). New York: Guilford Publications.
- Werner, E. E., & Smith, R. S. (1992). *Overcoming the odds: High risk children from birth to adulthood*. London: Cornell University Press.
- White, N. H., Sun, W., Cleary, P. A., Danis, R. P., Davis, M. D., Hainsworth, D. P., . . . Nathan, D. M. (2008). Prolonged effect of intensive therapy on the risk of retinopathy complications in patients with Type 1 diabetes mellitus: 10 years after the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications research group. *Archives of Ophthalmology*, *126*(12), 1707-1715. doi:10.1001/archophth.126.12.1707.
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with Type 1 diabetes. *The Diabetes Educator*, *38*, 562-579. doi:10.1177/0145721712445216
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research*, *18*(8), 1075-1083. doi:10.1177/1049732308320112
- World Health Organization (WHO). (2011). *Use of glycated haemoglobin (HbA1c) in the diagnosis of diabetes mellitus: Abbreviated report of a WHO consultation*. Retrieved from http://www.who.int/diabetes/publications/report-hba1c_2011.pdf
- Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2006). Getting out of the house: The challenges mothers face when their children have long-term care needs. *Health*

& *Social Care in the Community*, 15(1), 45-55. doi:10.1111/j.1365-2524.2006.00663.x

Yuwen, W., Chen, M. L., Cain, K. C., Ringold, S., Wallace, C. A., & Ward, T. M. (2016). Daily sleep patterns, sleep quality, and sleep hygiene among parent–child dyads of young children newly diagnosed with juvenile idiopathic arthritis and typically developing children. *Journal of Pediatric Psychology*, 41(6), 651-660. doi:10.1093/jpepsy/jsw007

Zan, H., & Scharff, R. L. (2015). The heterogeneity in financial and time burden of caregiving to children with chronic conditions. *Journal of Maternal Child Health*, 19, 615-625. doi:10.1007/s10995-014-1547-3

Zimmet, P., Alberti, K. G. M. M., & Shaw, J. (2001). Global and societal implications of the diabetes epidemic. *Nature*, 414, 782-787. doi:10.1038/414782a

CHAPTER 2: METHODOLOGY AND METHOD

A Qualitative Approach

Qualitative research takes an interpretive and naturalistic approach to the world. Phenomena are interpreted according to the meanings that people attach to them (Denzin & Lincoln, 2005). Rather than identifying cause-effect relationships, qualitative researchers place more emphasis on the quality and texture of experience (Willig, 2001). In qualitative methods, depth, openness and detail are the focus of inquiry (Patton, 2002). Depth is given greater primacy over breadth in qualitative research, where researchers are more interested in gathering in-depth and intimate information about a smaller group of people than drawing from a large, representative sample of the population of interest (Ambert, Adler, Adler, & Detzner, 1995). In addition, qualitative inquiry values the crucial role played by context, and how this can have an impact on the ways we describe and understand phenomena. Qualitative research is concerned with learning about how people make sense of their experiences rather than focusing on outsiders' views of what people do (Fiese & Bickham, 1998). Qualitative research emphasises the importance of exploring meaning, context and complexity in contrast to determining prevalence or cause and effect (Johnson, Burrows, & Williamson, 2004). This approach is appropriate to the aims of this research, to explore the lived experiences of parents who have a child with Type 1 diabetes.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was chosen to facilitate the exploration of lived experiences of the participants in this study. IPA is a relatively recent approach within qualitative inquiry. While the majority of studies using IPA have been within health psychology, it is increasingly being used in applied social and clinical psychology (Reid, Flowers, & Larkin, 2005). IPA involves a detailed exploration of the participant's view of the topic being investigated (Smith, Jarman, & Osborn, 1999). It commits to examining individuals' lived experiences in detail and understanding how individuals make sense of those experiences (Eatough & Smith, 2008). This approach is appropriate to the aims of the study to explore in detail what it is like for parents to care for a child with Type 1 diabetes, and what meanings parents construct out of their experience.

IPA's epistemological framework is informed by the two theoretical approaches of phenomenology and hermeneutics. Phenomenology is the philosophical movement

concerned with lived experience (Smith, 2011). It aims to achieve an understanding of the world as it is experienced by human beings within particular contexts and at particular times (Willig, 2001). In phenomenology, the focus is on exploring the individual's account of an object or event in contrast to creating an objective statement of the object or event (Smith et al., 1999). Edmund Husserl (1858-1938), the founder of phenomenology as a philosophical movement, asserts a core philosophical idea that there is nothing more fundamental than what is experienced (Moss, 2016). The term 'lived experience' has been used by researchers to represent the embodied, socio-culturally and historically situated person present in an intentionally interpreted and meaningfully lived world (Eatough & Smith, 2008). IPA addresses different aspects of this lived experience, ranging from individual's wishes, desires, feelings, motivations, and belief systems through to how these are translated into behaviour and action (Eatough & Smith, 2008).

Hermeneutics, the theory of interpretation, also plays a major role in IPA. This highlights the central role of the researcher as they try to get close to the participant's lived experience. A process of engagement and interpretation on the part of the researcher is required in order to gain access to the experiences of participants (Smith, 2011). Smith and Osborn (2008) propose that a double hermeneutic is involved in the interpretation process of IPA; while participants are trying to make sense of their world, the researcher is trying to make sense of the participants trying to make sense of their world. Access to someone else's experiences depends on and is complicated by the researcher's own conceptions (Smith et al., 1999) and the analytic account is always constructed together by both the participant and the researcher (Larkin, Watts, & Clifton, 2006). Interpretation is dependent upon the participants' abilities to express their thoughts and experiences and the ability of the researcher to reflect and analyse the experiences shared (Brocki & Wearden, 2006). The process of interpretation is dynamic and iterative; there is a circular interplay between parts and the whole and between the researcher and the researched (Shinebourne, 2011).

IPA is also theoretically influenced by idiography. In contrast to the traditional nomothetic study of people which attempts to establish general laws about human behaviour, the idiographic domain focuses on the particular and the individual (Smith, Harré, & Van Langenhove, 1995). Methodologically this leads to the relatively small number of participants involved in IPA studies, and the analysis of accounts being highly intensive and detailed (Larkin et al., 2006). In this approach, detailed examination of one case is carried out until some degree of resolution is reached, before moving on to the analysis of the second case and so on (Smith, 2004). Resolution in the context of IPA refers to the degree of closure or gestalt achieved out

of the data being analysed (Smith, 2004). This can be indicated when a summary of themes is developed for a data set. Another indication of this is when no new themes emerge upon multiple readings of the transcript. It is only then that an overall analysis across the cases is carried out for themes and patterns. Smith (2011) contends that IPA research should achieve a balance between convergence and divergence within the sample, by both presenting shared themes and signalling the specific ways in which these themes are relevant for the individuals.

Symbolic interactionism has also contributed to the development of IPA. Symbolic interactionism emphasises the importance of symbols and the interpretative processes that maintain interactions as fundamental to understanding human behaviour (Patton, 2002). Human beings are seen as creative agents who construct their social worlds through their inter-subjective interpretative activity (Eatough & Smith, 2008).

IPA and Health Research

IPA is increasingly being used in health psychology research, possibly due to its ability to contribute to biopsychosocial perspectives (Reid et al., 2005). Health psychologists aim to understand patient perceptions, their interpretations of bodily experiences and the meanings ascribed to them (Brocki & Wearden, 2006). IPA allows the exploration of these subjective experiences and is a way of describing participants' accounts in their particular contexts. It is especially valuable in exploring topics which are complex, ambiguous and emotionally laden (Smith & Osborn, 2015). Thus, IPA has become a popular method within chronic illness research to understand how individuals make sense of their illness experience. For example, IPA has been used to describe the debilitating impact of chronic pain on individuals' sense of self (Smith & Osborn, 2007) and the on-going struggle for patients living with chronic renal failure in attaining a sense of control (Lindsay, MacGregor, & Fry, 2014). These findings provide additional insights into the experience of living with a chronic illness to assist service providers develop better support.

Family caregiving experiences have also been explored using IPA. Explorations of how family caregivers of people with stroke or dementia make sense of their caregiving experiences reveal different coping strategies and the individual nature of sense making for each carer (Williams, Morrison, & Robinson, 2012). Aspects of the burden of caregiving and elements of support have also been described by parents of adult children with schizophrenia (Pike, 2013). These findings have implications for developing better support services for these families, and suggest that IPA is a suitable approach for exploring the multifaceted experience of caregiving.

IPA is also increasingly being used to explore experiences of parenting children with chronic conditions. The roles and responsibilities within the family of fathers caring for children with acute lymphoblastic leukaemia have been highlighted (Hill, Higgins, Dempster, & McCarthy, 2009). The complexities involved in managing cystic fibrosis has been explored in another study, where the findings emphasised the central role of parents in decision-making and treatment planning (Glasscoe & Smith, 2011). In addition, IPA research has drawn attention to aspects of adjustment and social implications for parents caring for children with severe food allergy (Rouf, White, & Evans, 2011). The literature on the experience of parenting children with autism has also benefitted from studies utilising IPA. The significant impact on the lives of mothers caring for children with autism and the ways that their caring role goes beyond the typical parenting role has been emphasised (Safe, Joosten, & Molineux, 2012). The impact of children's behaviour on parental functioning and wellbeing has been described for fathers caring for children with autism (Martins, Walker, & Fouché, 2013). The use of IPA in these studies allowed an in-depth exploration of the meanings ascribed to the parenting experience and illuminate the psychosocial impact and consequences of caring for a child with a chronic illness.

Reasons for Choosing IPA

IPA was chosen as the specific method of analysis for this research for several reasons. Firstly, this method will enable an in-depth examination of the experience of parents when they have a child diagnosed with Type 1 diabetes. The emphasis on the lived experiences makes this approach particularly suited to the aim of enhancing the understanding of what these experiences mean for them. Further, the interpretive element of IPA allows analysis to go beyond a simple description to consider the ways that parents make sense of their experiences. It provides an opportunity for the researcher to place the parents' accounts within the wider social, cultural and theoretical context (Larkin et al., 2006). This allows the parents' accounts to be situated within the context of their lived worlds (Palmer, Larkin, de Visser, & Fadden, 2010). This facilitates a critical analysis of the parents' accounts by drawing attention to the influences that shaped their sense-making. In addition, the idiographic approach of IPA would help understand parental experiences within their individual contexts. This also highlights the role of symbolic interactionism as the relationship between parental experiences and their contexts, and the meanings that parents assign to these experiences comes to the fore.

Further, IPA is also useful for exploring process. Rich information about the process of adjustment can be provided by IPA in contrast to methods that may emphasise

adjustment outcomes (Thompson, Kent, & Smith, 2002). For the current study, the focus on the processes of coping and adapting to having a child with Type 1 diabetes rather than their adjustment outcome is more salient. Finally, IPA is characterised as an inductive approach; IPA does not test hypotheses or a priori assumptions (Reid et al., 2005). This means that the researcher is able to explore phenomena without being constrained by these assumptions and, through exploration, develop new insights. These characteristics match the aims of this research, where further detailed and situated understanding of the parental experiences of having a child with Type 1 diabetes is sought.

Method

Participants

Participant Criteria

Participants in this study were parents of children aged between 4-12 years who had been diagnosed with Type 1 diabetes for a minimum of six months. It was decided that narrowing the range to this age group would restrict the group to children with more similar developmental needs and more consistency in the level of care. Children under four years were excluded from the study after careful consideration. This age group poses additional challenges to caregiving and diabetes management due to the child's limited cognitive and communication skills, and 'finicky' eating (Smaldone & Ritholz, 2011). Younger children have less understanding of their condition which can contribute to difficulty in recognising early signs of hypoglycaemia, getting the child's cooperation with uncomfortable procedures and accepting reasons for dietary restrictions (McDougal, 2002). Diabetes management is made more complex by issues such as the need to administer and adjust small doses of insulin, and practical aspects of care such as meal planning and blood glucose monitoring is also made more difficult (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002). Parents of younger children also bear complete responsibility for diabetes care, where they attend to constant and unrelenting demands of daily management (Monaghan, Hilliard, Cogen, & Streisand, 2011). The constant care can mean extra vigilance and inability to take breaks for the parents. These additional challenges make the experience of caregiving for a younger child more complicated, demanding and stressful. As such, these additional challenges can contribute to a different parenting experience, setting them apart from the experience of caring for an older child. Hence, to allow for the exploration of more comparable parental experiences, this age group was excluded.

Parents play a significant role in the management of diabetes in children from birth to adolescence. Adolescents are generally encouraged to become independent in their self-management, and can become less reliant on parents with day-to-day management (Spencer, Cooper, & Milton, 2013). Parents still play an important role in supporting adolescents in self-managing their condition, as parents can experience worry that adolescents may neglect self-care routines due to pressures and changes related to normal adolescent development (Moore, Hackworth, Hamilton, Northam, & Cameron, 2013). In the current study, the upper age limit of 12 years was chosen to reflect this developmental shift in the level of care provided by parents.

Participant Recruitment

Participants were recruited through three main avenues, the Diabetes Lifestyle Centre (DLC), Hawke's Bay diabetes service and the diabetes service at the Whanganui Hospital. The DLC is a service based at the Palmerston North Hospital operating under the MidCentral District Health Board. The centre provides specialist care for people with diabetes, covering the population living in Palmerston North city and surrounding districts. Amongst their services, they offer specialised clinical and educational programmes to meet the needs of children and adolescents with Type 1 diabetes, including insulin pump therapy and intensive insulin therapy (MidCentral District Health Board, 2014). The centre mailed out the Information Sheet for the study to families in their database meeting the study criteria, along with a covering letter (see Appendix A and Appendix B). Parents interested in taking part in the study were asked to send their contact information to the researcher in a postage-paid envelope. From this service, seven parents expressed interest in taking part in the research. As no further participants were able to be recruited from this area, recruitment was expanded to include Hawke's Bay and Whanganui.

The diabetes service based at Hawke's Bay Hospital also provides services for individuals with diabetes (Our Health Hawke's Bay, 2015). Here, information sheets were sent to 25 families who met the criteria for the study, and seven parents approached the researcher wanting to take part in the research. Five families were approached from the diabetes service at Whanganui Hospital, from which two corresponded with the researcher volunteering to take part. Recruitment was stopped at 17 parents, as it provided sufficient data to explore similarities and differences across parental experiences, across the three regions accessed.

Several steps were taken to raise awareness about the study to improve recruitment. The Manawatu Horowhenua Tararua Diabetes Trust provided invaluable support with this task. Established in 2000, this service provides support within the districts of

Manawatu, Horowhenua and Tararua regions. They provide consumer education, diabetes information and carry out child, youth and young adult education and activities (Manawatu Horowhenua Tararua Diabetes Trust, 2016). The Youth Coordinator of this service introduced the study in their support group meetings and provided information sheets to families who fit the criteria and were interested in taking part in the research. In addition to this, key personnel working at the three main services approached for recruitment were provided with a flyer containing information about the study (see Appendix C). A poster about the study was developed and displayed at both the DLC and the Diabetes Trust (see Appendix D). Furthermore, the study was advertised in the local news media describing the objectives of the study and criteria for participation. Three families were recruited into the study in this manner.

Participant Characteristics

A total of 17 parents (14 mothers and three fathers) were interviewed. While the study information sheet invited both parents to participate, in the majority of families, mothers volunteered to take part. Both parents were interviewed at the same time in two interviews. Eight interviews were conducted in Palmerston North and the surrounding areas, two in Whanganui and five in Hawke's Bay. All participants were the biological parents of the child with diabetes and lived in the family home. Except for one parent, all other parents had more than one child living at home. In terms of education level, eleven parents had completed high school and five parents had tertiary qualifications. In two cases, the child with diabetes was home-schooled by the parent. One parent had two children diagnosed with Type 1 diabetes. Although the older sibling was over 12 years and did not meet the study criteria, the parent was included in the analysis as the younger child's age was within the inclusion range. There was a significant range in age at diagnosis from one year and two months to 10 years. Only five children were using an insulin pump. Other health conditions present in the children included coeliac disease or epilepsy. Table 1 summarises the general participant characteristics and Table 2 provides further participant information.

Procedure

The current study involved in-depth semi-structured interviews. Semi-structured interviewing is the most common method of collecting data in qualitative psychological research (Willig, 2001). It has also been the method of choice in most studies using IPA as an approach (Smith & Osborn, 2008). This method presents an opportunity to elicit participant talk regarding a particular aspect of their life or experience (Willig, 2001). By using semi-structured interviews, researchers are able to gain a more elaborate

picture of participants' beliefs, perceptions or accounts of a particular topic, due to the flexibility this method provides in contrast to the more conventional structured interview (Smith, 1995). This flexibility is demonstrated by the way that the interviewer uses the interview schedule or agenda. In semi-structured interviewing, researchers have a list of questions on an interview schedule or agenda, which provides a guide rather than a strict schedule (Smith & Osborn, 2008). Within this framework, the interviewer is free to explore, probe and ask questions that will elucidate and illuminate the particular topic (Patton, 2002). The schedule may use a relatively small number of open-ended questions (Willig, 2001). The open-ended questions set the stage for exploration of the topic under investigation, and also allow participants to express novel insights into the subject matter.

Table 1

Demographic Characteristics of Participants and their Children

| | <i>N</i> | Mean | Range |
|-------------------------------|----------|------|----------|
| Parents | 17 | | |
| Parental age (years) | | 40 | 28-54 |
| Relationship to child | | | |
| Mother | 14 | | |
| Father | 3 | | |
| Ethnicity | | | |
| New Zealand European | 15 | | |
| New Zealand Māori | 1 | | |
| Other European | 1 | | |
| Relationship status | | | |
| Married/cohabiting | 13 | | |
| Separated/divorced | 4 | | |
| Employment | | | |
| In paid employment | 9 | | |
| Not in paid employment | 8 | | |
| Children | 15 | | |
| Child's age (years) | | 9 | 5-12 |
| Child's gender | | | |
| Female | 8 | | |
| Male | 7 | | |
| Age at diagnosis (years) | | 4.50 | 1.16- 10 |
| Duration of diagnosis (years) | | 4 | 0.75-9.5 |

A semi-structured interview schedule was developed for the current study by consulting the relevant literature (see Appendix E). The questions on the schedule were designed to stimulate and guide the participants' talk about their experiences of having a child with Type 1 diabetes. The parents were asked about their child's diagnosis of Type 1 diabetes, the specific concerns and the different challenges they face in their parenting, adjustment and coping, family strengths and advice for other

parents of children with Type 1 diabetes. Participants were encouraged and given the opportunity to raise issues salient to them at any point through the interview process.

Table 2

Further Participant Information

| No. | Relationship with child | Relationship status | Employment status | Age of child with diabetes | Age of child at diagnosis | Other health conditions of child |
|-----|-------------------------|---------------------|-------------------|----------------------------|---------------------------|----------------------------------|
| 1 | Mother | Married | Not employed | 5 years | 3 years | None |
| 2 | Mother | Married | Employed | 12 years | 4 years | Present |
| 3 | Mother | De-facto | Employed | 12 years | 8 years | None |
| 4 | Mother | De-facto | Employed | 11 years | 4 years | None |
| 5 | Mother | Married | Employed | 9 years | 8 years | Present |
| 6 | Mother | Married | Not employed | 9 years | 2 years | Present |
| 7 | Father | Separated | Not employed | 7 years | 4 years | None |
| 8 | Mother | Divorced | Not employed | 12 years | 2 years | Present |
| 9 | Mother | Separated | Employed | 5 years | 3 years | None |
| 10 | Mother | Separated | Not employed | 8 years | 4 years | None |
| 11 | Mother | Married | Employed | 11 years | 10 years | Present |
| 12 | Mother | Married | Not employed | 5 years | 1 year | None |
| 13 | Mother | Married | Employed | 9 years | 7 years | None |
| 14 | Father | Married | Employed | (as above) | | |
| 15 | Mother | Married | Not employed | 7 years | 4 years | None |
| 16 | Mother | Married | Not employed | 11 years | 4 years | None |
| 17 | Father | Married | Employed | (as above) | | |

Participants were given the choice of selecting a location that was convenient to them for the interview. Fourteen interviews were conducted in the participants' own homes, and one interview was conducted at a participant's workplace. At the start of the interviews, participants were asked whether they had any questions regarding the study, and a consent form was signed (see Appendix F). Parents were offered a \$30 petrol voucher as compensation for their time and effort. The interviews lasted between 45 minutes to 2 hours. Interviews were digitally recorded and transcribed verbatim. Transcripts were reviewed to ensure accuracy. A copy of the transcript was made available to those who requested (see Appendix G). No participants contacted the researcher with any changes.

Data collection commenced in May 2012 and was completed in November 2012. The research was carried out in two phases: a pilot phase and a main study phase. A pilot phase was used to assess any issues or barriers in the recruitment process and to trial the semi-structured interview schedule for feedback on interview questions. The interview schedule was piloted with the first three participants. There are a number of

practical reasons for conducting pilot works in qualitative inquiry (Kim, 2011). One useful aspect is that it can help novice researchers in assessing and preparing their interview and observation techniques. Pilot works also provide the researcher with the opportunity to test out the sampling procedure and address barriers that could affect the main study. The pilot phase in the current study addressed these aspects. The questions on the interview schedule were appropriate and sufficient and did not require major changes. Subsequently, the pilot phase data was treated as part of the main corpus of data.

Data Analysis

Data analysis was commenced after the completion of all interviews. The interview transcripts were analysed using IPA by following a series of steps as described by Smith and Osborn (2008). It is advised that analysis should begin by looking into the themes of one interview before moving on to the next (Smith & Osborn, 2008). The first stage of analysis involved reading the transcript several times, becoming familiar with it and noting down any important aspects of the data on the margin of the page. These comments included initial thoughts and observations, preliminary interpretations, and aspects of data that were interesting or significant. Next, emerging themes were noted down on the side of the page. Here, the initial notes and ideas were transformed into more specific themes or phrases related to psychological concepts and abstractions (Smith & Eatough, 2006). A theme describes an aspect of the structure of the lived experience (van Manen, 1990). Following this, themes were clustered by connecting them together. The clusters should capture the main categories of meaning conveyed by the participant (Willig, 2001). A descriptive label was given to each cluster to express the conceptual nature of the themes involved (Smith & Eatough, 2007).

Smith and Osborn (2008) assert that IPA is not a prescriptive methodology and that the series of steps described are merely guidelines which can be adapted by researchers. In the current study, after following the above series of steps with each individual transcript, the next stage involved closely examining the most salient clusters of themes, attempting to identify shared experiences across the large number of participants (Smith et al., 1999). The selection of the most salient clusters for more detailed analysis assisted in the production of a manageable number of themes, to represent a more thorough and synthesised analysis (Hefferon & Gil-Rodriguez, 2011). Once a cluster was chosen for further analysis, the transcripts were examined one by one and extracts that were coded under the particular theme were compiled into a new file. Each extract was labelled with the participant number. Extracts that belonged to other related concepts that were not previously coded under the theme were also

identified and copied to the new file. Once this new corpus of data was collated, the file was printed out for further analysis. Each individual extract was then analysed and coded. Closely related codes were grouped together to form themes. The final stage involved transforming this structure of themes into the write-up of the results. Analysis continued during the writing phase, where the themes were further developed and refined. Particular extracts were chosen over others to demonstrate each theme. This process involved considering the immediacy and articulacy with which some participants expressed a point, which made some extracts a better exemplar over others in portraying the theme (Brocki & Wearden, 2006).

There were several considerations in evaluating the importance of themes. Themes were not selected just on the basis of prevalence alone (Brocki & Wearden, 2006). The importance of a theme is not limited to its frequency in the data, it should rather encapsulate something significant in relation to the overall research question (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Another consideration was how well the theme illuminated other aspects of the account (Smith et al., 1999). In this sense, themes that shed additional insight on the main account may be analysed in more detail even when their prevalence in the data may not be high.

In the reporting of the results of the study, the selected extracts were edited to ensure confidentiality. All personal and identifying information was removed and pseudonyms placed where people's names appeared. The interviewer's questions and comments appeared within curly brackets { }. In the extracts from the two interviews where both parents participated, the fathers' comments appeared within round brackets (). Observations during the interview, such as pauses and participant reactions such as laughter, were indicated inside square brackets [].

Participants were sent a preliminary summary of results at the end of 2013 (see Appendix H).

Ethical Issues

Ethical approval was granted by the Central Regional Ethics Committee of the Health and Disability Ethics Committees in November 2011, reference CEN/11/EXP/085 (see Appendix I). The Kaumatua for the School of Psychology at Massey University, Harawira Turoa Haronga, was consulted in the development of the study to review any considerations in relation to participation by Māori families. Participants were recruited under voluntary participation with informed consent. They were provided with an information sheet outlining the aims and details of the study, and issues of confidentiality. Confidentiality was ensured by recording participant numbers instead

of participants' names and with the anonymous use of quotes when reporting the results of the study. No identifying information was included in the transcripts of the interviews or in any of the reports that arose from the study.

Enhancing Quality in Qualitative Research

Various guidelines have been developed to assess the rigor and trustworthiness of qualitative inquiries (Elliot, Fischer & Rennie, 1999; Guba, 1981; Tracy, 2010; Yardley, 2008). These guidelines have been developed as a response to increasing debate over appropriate criteria for evaluating qualitative research. The principles suggested by Yardley (2000, 2008) were used to guide this study. The four broad principles are sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance.

The current study demonstrates sensitivity to context by being aware of the socio-cultural setting of the study, which involved being mindful of the normative, historical, linguistic, and socioeconomic influences on participants' accounts (Yardley, 2000). Attention was paid to the social context of the data gathering, where appropriate procedures were followed to gain access to participants through the established healthcare and service pathways. Another consideration of the social context involved being aware of the relationship between the researcher and the participants and the potential effects of researcher characteristics on the study (Yardley, 2000). These considerations are addressed in the Reflexivity section in the Discussion chapter (page 149). Sensitivity to the theoretical context of the study was demonstrated by reviewing the existing literature on the parental experiences in childhood diabetes to identify gaps in current understandings. The consideration of the theoretical context was also important in discussing the implications of the results for clinical practice.

The study also shows commitment and rigor in several ways. The researcher demonstrated in-depth and prolonged interest and engagement with the topic of lived experiences of parents of children with Type 1 diabetes. A systematic approach was employed throughout the research process in reviewing the literature, collecting and analysing the data, and writing-up the results. A thorough data collection phase, using measures to improve recruitment to ensure sufficient data was collected, and conducting in-depth interviews further enhanced the commitment and rigor of the study. Taking fieldnotes after each interview provided an opportunity for the researcher to reflect on the ways that participants responded during the interview and note other interesting observations. The interviews were transcribed verbatim, reflecting attention to detail, while steps were taken to ensure the accuracy of the transcripts. Rigor during analysis involved being clear about the processes of sorting

and organising the data (Tracy, 2010). Considerable time was spent reading and re-reading transcripts alongside the developing themes, to find additional support for themes or instances of divergences. Regular discussions with members of the supervisory team assisted in critically assessing whether the interpretations were supported by the direct quotes. Furthermore, these discussions involved mapping and revising developing themes as analysis progressed. In the write-up, thick descriptions of participants' contexts, research setting and procedures are provided for better clarity (Krefting, 1991).

Transparency has been described as honesty about the research process (Tracy, 2010). Assumptions, intentions and actions of the researcher can influence the product of any research (Yardley, 2000). Being transparent about these factors can help readers understand the influence of researchers' characteristics on the research process. These aspects are addressed in the Reflexivity section in the Discussion chapter (page 149). The transparency of the study was also helped by keeping a self-reflective diary to document the analytic decision-making processes and minimize researcher bias. A reporting bias could have occurred if the researcher did not consider the more difficult experiences of the parents, and only analysed the positive experiences. The research sample, settings and procedures were described in sufficient detail to establish a transparent process. During data analysis, care was taken to sufficiently describe the pathway from data to conclusions (Meyrick, 2006). This was supported by using participants own words in direct quotes, and providing examples where possible to support the analytic claims made. Regular discussions with the supervisory team also aided transparency by ensuring that the study sufficiently described the rationale for the procedures undertaken. Transparency of the study was also demonstrated by the ways that the study described how its focus transformed over time, as the study progressed (Tracy, 2010).

The coherence of a study can be described as the extent to which it makes sense as a consistent whole (Yardley, 2008, p.248). Coherence of the current study was enhanced by regular feedback from the supervisory team to ensure the plausibility of the developing interpretations and clarity of arguments presented in the thesis. Coherence can also be demonstrated by the 'fit' between the research question and methods chosen (Yardley, 2000). As such, IPA appeared as a good fit between the research question and the method by being a suitable method for exploring parents' lived experiences of caring for a child with Type 1 diabetes.

The impact and importance of research relate to the potential of its findings to make a difference (Yardley, 2008). In terms of practical utility, it is hoped that the findings of

the current study will improve the current understanding of the experiences of parenting a child with Type 1 diabetes, and parenting a child with a chronic condition more generally. This has the potential to improve practice with these families, where knowing more about the lived experiences of these parents can make health professionals more empathic and understanding of each family's unique adjustment to an illness. The study also demonstrates theoretical significance by building on past research and extending the current knowledge of the experience of caring for children with Type 1 diabetes.

References

- Ambert, A., Adler, P. A., Adler, P., & Detzner, D. F. (1995). Understanding and evaluating qualitative research. *Journal of Marriage and Family*, *57*(4), 879-893. doi:10.2307/353409
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, *21*(1), 87-108. doi:10.1080/14768320500230185
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd d., pp. 1-32). Thousand Oaks, California: Sage Publications.
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). Los Angeles: Sage Publications.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215-229. doi:10.1348/014466599162782
- Fiese, B. H., & Bickham, N. L. (1998). Qualitative inquiry: An overview for pediatric psychology. *Journal of Pediatric Psychology*, *23*(2), 79-86. doi:10.1093/jpepsy/23.2.79
- Glasscoe, C., & Smith, J. A. (2011). Unravelling complexities involved in parenting a child with cystic fibrosis: An interpretative phenomenological analysis. *Clinical Child Psychology and Psychiatry*, *16*(2), 279-298. doi:10.1177/1359104510383207
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ*, *29*(2), 75-91. doi:10.1007/bf02766777
- Hefferon, K., & Gil-Rodriguez, E. (2011). Methods: Interpretative phenomenological analysis. *The Psychologist*, *24*(10), 756-759.
- Hill, K., Higgins, A., Dempster, M., & McCarthy, A. (2009). Fathers' views and understanding of their roles in families with a child with acute lymphoblastic leukaemia. *Journal of Health Psychology*, *14*(8), 1268-1280. doi:10.1177/1359105309342291

- Johnson, S., Burrows, A., & Williamson, I. (2004). 'Does my bump look big in this?' The meaning of bodily changes for first-time mothers-to-be. *Journal of Health Psychology, 9*(3), 361-374. doi:10.1177/1359105304042346
- Kim, Y. (2011). The pilot study in qualitative inquiry: Identifying issues and learning lessons for culturally competent research. *Qualitative Social Work, 10*(2), 190-206. doi:10.1177/1473325010362001
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214-222. doi:10.5014/ajot.45.3.214
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120. doi:10.1191/1478088706qp062oa
- Lindsay, H., MacGregor, C., & Fry, M. (2014). The experience of living with chronic illness for the haemodialysis patient: An interpretative phenomenological analysis. *Health Sociology Review, 23*(3), 232-241. doi:10.1080/14461242.2014.11081976
- Manawatu Horowhenua Tararua Diabetes Trust. (2016). *Diabetes trust*. Retrieved from <http://www.diabetestrust.org.nz/>
- Martins, C. D., Walker, S. P., & Fouché, P. (2013). Fathering a child with autism spectrum disorder: An interpretative phenomenological analysis. *Indo-Pacific Journal of Phenomenology, 13*, 1-19.
- McDougal, J. (2002). Promoting normalization in families with preschool children with Type 1 diabetes. *Journal for Specialists in Pediatric Nursing, 7*(3), 113-120. doi:10.1111/j.1744-6155.2002.tb00160.x
- Meyrick, J. (2006). What is good qualitative research? *Journal of Health Psychology, 11*(5), 799-808. doi:10.1177/1359105306066643
- MidCentral District Health Board. (2014). *Diabetes*. Retrieved from <http://www.midcentraldhb.govt.nz/HealthServices/MedicalServices/Pages/Diabetes.aspx>
- Monaghan, M., Hilliard, M., Cogen, F., & Streisand, R. (2011). Supporting parents of very young children with type 1 diabetes: Results from a pilot study. *Patient Education and Counseling, 82*(2), 271-274. doi:10.1016/j.pec.2010.04.007
- Moore, S. M., Hackworth, N. J., Hamilton, V. E., Northam, E. P., & Cameron, F. J. (2013). Adolescents with Type 1 Diabetes: Parental perceptions of child health and

- family functioning and their relationship to adolescent metabolic control. *Health & Quality of Life Outcomes*, 11(1), 1-8. doi:10.1186/1477-7525-11-50
- Moss, J. (2016). Experience sampling methods in critical event studies: Theory and practice. In I. R. Lamond & L. Platt (Eds.), *Critical event studies: Approaches to research* (pp. 253-276). London: Palgrave Macmillan.
- Our Health Hawke's Bay. (2015). *Diabetes services*. Retrieved from <http://www.ourhealthhb.nz/health-services/ages-and-stages-in-health/diabetes-services/>
- Palmer, M., Larkin, M., de Visser, R., & Fadden, G. (2010). Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology*, 7(2), 99-121. doi:10.1080/14780880802513194
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, California: Sage Publications.
- Pike, B. (2013). *Caregiver experiences of parents who support adult children with schizophrenia*. (Unpublished master's thesis). Auckland University of Technology, Auckland, New Zealand.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *Psychologist*, 18(1), 20-23.
- Rouf, K., White, L., & Evans, K. (2011). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology and Psychiatry*, 17(1), 49-64. doi:10.1177/1359104511415636
- Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability*, 37(4), 294-302. doi:10.3109/13668250.2012.736614
- Shinebourne, P. (2011). The theoretical underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis*, 22(1), 16-31.
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of parenting children with Type 1 diabetes diagnosed early in childhood. *Journal of Pediatric Health Care*, 25(2), 87-95. doi:10.1016/j.pedhc.2009.09.003
- Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harré, & L. Van Langenhove (Eds.), *Rethinking methods in psychology* (pp. 9-26). London: Sage Publications.

- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54. doi:10.1191/1478088704qp004oa
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria. *Health Psychology Review*, 5(1), 55-61. doi:10.1080/17437199.2010.541743
- Smith, J. A., & Eatough, V. (2006). Interpretative phenomenological analysis. In G. M. Breakwell, S. Hammond, C. Fife-Schaw & J. A. Smith (Eds.), *Research methods in Psychology* (3rd ed., pp. 322-341). London: Sage.
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in Psychology* (pp. 35-50). Los Angeles: Sage.
- Smith, J. A., Harré, R., & Van Langenhove, L. (1995). Idiography and the case study. In J. A. Smith, R. Harré & L. Van Langenhove (Eds.), *Rethinking psychology* (pp. 59-69). London: Sage.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology* (pp. 218-240). Thousand Oaks: Sage Publications.
- Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health*, 22(5), 517-534. doi:10.1080/14768320600941756
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London: Sage.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, 9(1), 41-42. doi:10.1177/2049463714541642
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing*, 18(1), 21-29. doi:10.1053/jpdn.2003.4
- Spencer, J. E., Cooper, H. C., & Milton, B. (2013). The lived experiences of young people (13-16 years) with Type 1 diabetes mellitus and their parents- A qualitative phenomenological study. *Diabetic Medicine*, 30(1), e17-e24. doi:10.1111/dme.12021

- Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7(2), 213-225. doi:10.1348/135910702169457
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851. doi:10.1177/1077800410383121
- Vaismoradi, M., Jones, J., Turunen, H., & Snelgrove, S. (2016). Theme development in qualitative content analysis and thematic analysis. *Journal of Nursing Education and Practice*, 6(5), 100-110. doi:10.5430/jnep.v6n5p100
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London: State University of New York Press.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Philadelphia: Open University Press.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228. doi:10.1080/08870440008400302
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 235-251). London: Sage.

OUTLINE OF RESULTS

The present study aimed to explore the lived experiences of parents caring for a child with Type 1 diabetes. The results of the analysis are presented across the next three chapters to describe different aspects of the overall parental experience. These chapters are presented as individual manuscripts written for publication.

Table 3 outlines the main themes and the subthemes presented in these chapters. These represent the most salient themes that captured the essence of parental experiences. Themes are complex and interdependent and as such, the organisation of these themes into the current structure represents analytic distinctions, shaped by the focus of each paper.

Table 3

Main Themes and Sub Themes

| Chapter | Main Theme | Sub Themes |
|---------|--|--|
| 3 | Issues of embodiment | <ul style="list-style-type: none">• Constant vigilance and better management• Comparing diabetes with other conditions |
| 4 | Impact on parental identity and repair | <ul style="list-style-type: none">• A new baby- A transitional moment• In pursuit of normality |
| 5 | Conceptualising parental resilience | <ul style="list-style-type: none">• Parental accounts of resilience• 'Doing' resilience• Processes that help with 'doing' resilience |

The first paper has a particular focus on the physical aspects of the parental experience and discusses embodiment in the context of caring for a child with Type 1 diabetes. This paper is presented first as it provides a useful description of the parents' everyday lived experience. The second paper describes the impact of the diagnosis of Type 1 diabetes by discussing the biographical disruption that occurred for the parents and the associated impact on parental identity. The third paper addresses a particular aim of the current study to explore parental resilience and describes the ways that parents understood resilience, and an alternative way of conceptualising resilience for these parents.

CHAPTER 3: THE PARENTAL EXPERIENCE OF CARING FOR A CHILD WITH TYPE 1 DIABETES

This chapter is based on the paper that is published in the *Journal of Child and Family Studies*, at <https://link.springer.com/article/10.1007/s10826-017-0806-5>. The full reference for this article is as follows:

Rifshana, F., Breheny, M., Taylor, J., & Ross, K. (2017). The parental experience of caring for a child with Type 1 diabetes. *Journal of Child and Family Studies*. Advance online publication. doi: 10.1007/s10826-017-0806-5

Abstract

Type 1 diabetes is the most common chronic metabolic condition seen in children and adolescents. Parents play an instrumental role in caring for a child with Type 1 diabetes. The present study aimed to explore experiences of parents as they look after their child who has a body that presents unique challenges to both maintaining health and meeting expectations for a conventional childhood. This qualitative study involved in-depth semi-structured interviews with 17 parents of children with Type 1 diabetes. Interpretative Phenomenological Analysis (IPA) was used to analyse parents' accounts to elicit salient themes. Parents described how they responded to some of the embodied experiences of their child, through their own embodied acts of caregiving. Looking after a child with diabetes was a demanding experience, where the illness experience was dominated by the 'constant-ness' of the disease. This experience was heavily driven by a need for constant vigilance and careful management in the context of an unpredictable body. Parents also made comparisons of their child with a diabetic body with other types of health conditions and situations, to arrive at two different positions; one where they saw diabetes as a fortunate diagnosis compared to other childhood conditions, and the alternative position that diabetes was more challenging to live with than other illnesses. These comparisons provide a way of coping with the embodied unpredictability of childhood diabetes. Rather than viewing these comparisons as adaptive or maladaptive, health professionals may be able to understand the competing and contradictory accounts that parents provide as they attempt to make sense of the experience of parenting a child with a chronic illness.

Introduction

Type 1 diabetes mellitus is the most common chronic metabolic condition seen in children and adolescents (Shulman & Daneman, 2010). Worldwide, the incidence of Type 1 diabetes has risen by 3.4% annually during the years 1995-1999 (DIAMOND Research Group, 2006). The International Diabetes Federation (IDF) estimated that 86,000 children between the ages of 0-14 would be newly diagnosed with Type 1 diabetes in 2015 globally, with the highest incidence rates estimated for Finland, Sweden and Kuwait (IDF, 2015). The incidence of Type 1 diabetes increases with age, with the highest incidence observed in children aged 10–14 years (Maahs, West, Lawrence, & Mayer-Davis, 2010).

Type 1 diabetes is characterised by an autoimmune-mediated destruction of pancreatic β -cells, causing absolute insulin deficiency (Zimmet, Alberti, & Shaw, 2001). The hormone insulin is responsible for the use of glucose in the body, and a lack of insulin leads to glucose not being used in the cells for energy, resulting in hyperglycaemia (Doyle & Grey, 2010). The excess glucose or sugar in the body can cause many complications and can be fatal. Treatment involves a regimen of insulin therapy, management of diet and activity levels, and glucose monitoring (Doyle & Grey, 2010). The ultimate goal of treatment is to maintain the blood glucose level at a healthy range, in order to lower the risk of future complications. Chronic high blood glucose levels can lead to complications such as eye problems and blindness, nerve damage, coronary artery disease, peripheral vascular disease, kidney disease and amputations (Trief et al., 2003). The maintenance of normal blood glucose levels with intensive therapy has been shown to effectively delay the onset and progression of such complications (de Boer et al., 2011; Pop-Busui et al., 2009).

The demands of the physical management of Type 1 diabetes can be incredibly difficult. Maintaining the child's blood glucose level within a healthy range poses a constant challenge, where carers need to closely monitor the child's activity, diet, insulin injections and blood glucose levels. Most children need more than one insulin injection per day, and their blood glucose levels need to be monitored several times each day (Falvo, 2009). Children and some adolescents cannot independently carry out all of their diabetes care (Silverstein et al., 2005). Consequentially, parents and caregivers of children with Type 1 diabetes tend to be heavily involved in the daily management of the disease.

Diabetes onset in a child has a significant impact on the parental caregiving experience. The diagnosis is marked by multiple losses for caregivers. Parents describe

the loss of their previously healthy child, their freedom, and a loss in their own confidence in parenting (Marshall, Carter, Rose, & Brotherton, 2009). Parents also express the loss of their child's independence and the loss of spontaneity (Lowe, Lyne, & Gregory, 2004). The sense of loss can be long lasting. Many parents were still cognizant about the loss of their healthy child, control, freedom, and confidence in protecting children from harm at 12 months after diagnosis (Lowe, Gregory, & Lyne, 2005). These findings suggest that parents not only suffer losses directly, but also bear the losses that impact on their children, and that the experience of loss can persist over time.

On-going stress and worry has been reported as a predominant experience for these parents that often relates to diabetes management and the potential for long-term complications (Buckloh et al., 2008). A daily stressor involves having to regularly inflict pain on their child through the blood sugar monitoring and insulin injections (Hatton, Canam, Thorne, & Hughes, 1995). Stress related to fear of hypoglycaemia is also common, especially during night time and naptime (Sullivan-Bolyai, Deatrck, Gruppuso, Tamborlane, & Grey, 2003). Parents describe being 'constantly vigilant', in ensuring that diet and activity are appropriate and blood glucose readings are within the healthy range in order to avoid hyperglycaemia and hypoglycaemia (Sullivan-Bolyai et al., 2003), with constant checking providing them with reassurance (Marshall et al., 2009). Thus, qualitative research on Type 1 diabetes has tended to focus on managing the psychosocial challenges involved in the parenting experience. One line of research that has received insufficient attention is issues of embodiment within the caregiving experience.

Embodiment refers to the assumption that thoughts, feelings, and behaviours are grounded in our bodily interaction with the environment (Meier, Schnall, Schwarz, & Bargh, 2012). Our living bodies can tell stories about our lives (Krieger, 2004). "Our bodies are not normally acknowledgeable to us as objects in the world because we live and act through them, but in the case of illness or injury, the body can appear alienated and objectified and threaten our usual sense of being in the world" (Nexø et al., 2015, p.946). Past research on chronic illness has looked at the ways that patients embody their illness experience. Carel (2013) studied embodied experiences in the context of illness, and proposed that a change to a bodily function can result in a change to one's whole way of being, and also affect the meaning of experience. Illness can pose limitations on the body that undermine the certainty and trust we normally have in our bodies (Carel, 2013). Hence, exploring embodied dimensions in the context of illness can illuminate important aspects of the lived experience. Embodied

understandings serve as a “Geiger counter of meaning” (Raingruber & Kent, 2003, p.449) to access a rich insight into lived experiences.

Previous research has attempted to understand embodied experiences in the context of diabetes. Balfe (2009) explored the concept of ‘body projects’ among university students with Type 1 diabetes, and found that the students engaged in attempts to develop normal embodied identities that were unaffected by diabetes. These attempts could be difficult to sustain, however. Montez and Karner (2005) suggest that through the therapeutic regimen of focus on blood glucose readings and physical activities, the subjective and embodied experience of the person with diabetes can become lost. In their exploration of ‘ideal body types’ in individuals with diabetes, they found that more individuals embodied a ‘disciplined body type’ in contrast to a ‘communicative body type’. This meant that individuals were more focused on strict blood sugar control rather than a more balanced integration of control into everyday life, where the latter would facilitate a better integration with the social world they lived in. Therefore, exploring embodiment issues in terms of Type 1 diabetes can offer insights into the embodied and socially situated experiences of living with Type 1 diabetes.

While embodied understandings have been studied within Type 1 diabetes, there has been little attention to embodied experiences within parents’ narratives of caring for a child with Type 1 diabetes. Sparud-Lundin, Hallström, and Erlandsson (2013) described how manifestations of embodiment appeared in their study of parents with children recently diagnosed with Type 1 diabetes, through ways of regaining control in their daily life to manage the increased burden of caregiving.

Embodiment in children and parenting has been an underexplored area (Colls & Hörschelmann, 2009). Doucet (2006) highlights the importance of studying embodiment within caregiving, given the level of embodied interactions in families and how practices of caring for others are so intrinsically embodied. Individuals’ bodies are lived alongside and in response to other’s bodies, where each body’s ‘being-in-the-world’ is shaped by the other’s (Lupton, 2012). Bodies are central to the work of parenting (Kelly, 2005), and children’s embodiment can shape parental movements and thinking (Talbot, 2013). The physical, mental and emotional engagement with their child’s body is the engrossing and embodied activity of parenting (Kelly, 2005). The intersection between their child’s diabetic body and the parents’ own embodied and socially situated experiences of parenting offers an opportunity to understand the experiences of parenting as reflecting both biological processes and social expectations. The current paper aims to add to the literature on embodiment within

caregiving by exploring the lived experience of parents of children with Type 1 diabetes using the qualitative approach of Interpretative Phenomenological Analysis (IPA).

Method

Participants

Participants in this study were parents of children aged between four and twelve years who had been diagnosed with Type 1 diabetes for a minimum of six months. Participants were recruited from three main services that provide specialist care for people with diabetes in New Zealand. These services mailed out the information sheet for the study to the families in their database meeting the study criteria, along with a covering letter. Twenty parents contacted the researcher to express their interest in taking part in the study. A total of 17 parents (14 mothers and three fathers) were interviewed before data saturation had occurred. While the study information sheet invited both parents to participate, in the majority of families, mothers volunteered to take part. Both parents were interviewed at the same time in two interviews. One participant had two children diagnosed with Type 1 diabetes, with the younger child's age within the inclusion range. Table 1 summarises the participant characteristics.

Table 1

Demographic Characteristics of Participants and their Children

| | <i>N</i> | Mean | Range |
|-------------------------------|----------|------|----------|
| Parents | 17 | | |
| Parental age (years) | | 40 | 28-54 |
| Relationship to child | | | |
| Mother | 14 | | |
| Father | 3 | | |
| Ethnicity | | | |
| New Zealand European | 15 | | |
| New Zealand Māori | 1 | | |
| Other European | 1 | | |
| Relationship status | | | |
| Married/cohabiting | 13 | | |
| Separated/divorced | 4 | | |
| Employment | | | |
| In paid employment | 9 | | |
| Not in paid employment | 8 | | |
| Children | 15 | | |
| Child's age (years) | | 9 | 5-12 |
| Child's gender | | | |
| Female | 8 | | |
| Male | 7 | | |
| Age at diagnosis (years) | | 4.50 | 1.16- 10 |
| Duration of diagnosis (years) | | 4 | 0.75-9.5 |

Procedure

The present study involved in-depth semi-structured interviews, conducted by the first author. Parents selected a location that was convenient to them for the interview. Fourteen interviews were conducted in the parents' own homes, and one interview was conducted at a parent's workplace. Some interviews occurred in the presence of the child with diabetes or other children. Interviews were digitally recorded and transcribed verbatim by a professional transcriber. The transcripts were reviewed for accuracy by the first author. A copy of the transcript was made available to those who requested it. Data collection commenced in May 2012 and was completed in November 2012. Ethical approval was granted by the Central Regional Ethics Committee of the Health and Disability Ethics Committees.

Measures

An interview schedule with open-ended questions was used to guide the interview. These questions asked parents about their child's diagnosis of Type 1 diabetes (e.g., "Tell me about when you first found out that your child had diabetes. How did you know something was wrong? What did you do?"), the challenges they faced in their parenting ("What was the hardest part about it? Why was that difficult for you? What worries you the most about your child having diabetes?"), and their adjustment and coping ("How have you come to terms with your child having diabetes? What have you found helpful for coping? Why do you find that helpful?"). The questions were designed to stimulate and guide the participants' talk about their experiences of having a child with Type 1 diabetes. Participants were encouraged and given the opportunity to raise issues salient to them at any point during the interview. The interviews lasted between 45 minutes to two hours.

Data Analyses

IPA was chosen as the method of analysis for this research to enable an in-depth examination of the lived experiences of parents who have a child diagnosed with Type 1 diabetes. IPA commits to examining and understanding how individuals make sense of their lived experiences (Eatough & Smith, 2008). The term 'lived experience' has been used by researchers to represent the embodied, socio-culturally and historically situated person present in an intentionally interpreted and meaningfully lived world (Eatough & Smith, 2008). All experience must be seen in the context of the embodied and situated subject (Langdrige, 2008). IPA addresses different aspects of this lived experience, ranging from individual's wishes, desires, feelings, motivations, and belief systems through to how these are translated into behaviour and action (Eatough &

Smith, 2008). IPA is also useful for exploring process. Rich information about the process of adjustment can be provided by IPA (Thompson, Kent, & Smith, 2002), in contrast to methods that may emphasise adjustment outcomes. For the current study, the focus was on the processes of coping and adapting to having a child with Type 1 diabetes.

Data analysis was commenced after the completion of all interviews. The interview transcripts were analysed using IPA by following a series of steps as described by Smith and Osborn (2008). The first stage involved becoming familiar with the transcript and noting down any important aspects of the data on the margin of the page, including initial thoughts and observations, and preliminary interpretations. Next, emerging themes were noted down on the side of the page with initial notes transformed into more specific themes (Smith & Eatough, 2006). Following this, themes were clustered by connecting them together, capturing the main categories of meaning conveyed by the participants (Willig, 2001). A descriptive label was given to each cluster to express the conceptual nature of the themes involved (Smith & Eatough, 2007). At the end of the process, a summary of the higher-order themes was developed. The next stage involved closely examining the most salient higher-order themes. Once a theme was selected for further analysis, the transcripts were examined again to select the extracts coded under the theme, copying them into a new word-processed file. Each individual extract was then analysed and coded. Themes were then formed from closely related codes.

The rigor and trustworthiness of the current study was ensured by considering the guidelines for evaluating qualitative research suggested by Yardley (2000). Steps were taken to minimize researcher bias and enhance transparency. Self-reflective notes and summaries were kept by the first author to capture the development of the topic and the analytic decision-making processes. The first author coded the transcripts and developed the thematic framework. From this, all members of the research team contributed to developing the analysis and refining the interpretations to ensure the plausibility and transparency of the analysis. In the reporting of the results of the study, the selected extracts were edited to ensure confidentiality. All personal and identifying information was removed and pseudonyms placed where people's names appear. The interviewer's questions and comments appear within brackets { }. Observations during the interview, such as pauses and participant reactions, such as laughter are indicated inside square brackets [].

Results

A prominent theme, 'Looking after a child with diabetes: Issues of embodiment' is presented in detail below. Two specific aspects of this main theme, 'Constant vigilance and careful management' and 'Comparing diabetes with other conditions', are also discussed.

Looking After a Child with Diabetes: Issues of Embodiment

This prominent theme describes the lived experience of parents of caring for their child with diabetes. In particular, parents' accounts illuminated the embodied dimensions of a child with Type 1 diabetes, through their own embodied acts of caregiving. The caregiving experience involves a complex web of biological, physical and psychosocial aspects. Looking after a child with diabetes involved a series of procedures carried out by the parents, which were "literally keeping them alive with some difficulty" (Participant 7, Mother). This day-to-day management involved repeated blood sugar monitoring, insulin injections, and attention to diet and activity levels, to maintain the blood sugar readings within the normal range. The two accounts outlined below demonstrate daily routines of this regimen:

... she tests um definitely 8 times a day a day if not more. So that's before and after every meal, um morning tea, afternoon tea, night time, yeah, so quite routine [laugh]. (Participant 3, Mother: Daughter, 12 years).

...keeping them active is difficult. {Int: Yeah}. Um, and the whole balancing thing with food, activity and um, and the insulin, that's really, that, and that is still very tricky. Yeah. (Participant 10, Mother: Son, 8 years).

The diabetic body displays a fragile balance between food intake, insulin injections, and activity. The focus of these accounts is on the parents' role in ensuring activity and managing the complex interactions of diet, activity and medication in their child. The most striking aspect of this is the notion of the "constant-ness" of diabetes, coined by one parent to describe the constant and demanding aspects of the condition:

It's more the, the hardest thing for me about diabetes is the daily constant-ness of it. That you can't have a day off, and you can't go actually I'm not doing this today. I can't be bothered. (Participant 5, Mother: Daughter, 8 years).

This mother highlights the lack of options in dealing with the disease on a daily basis. The concept of "constant-ness" demonstrates how the demands of the diabetic body are ever-present, leading to a high degree of parental involvement, and a lack of

respite for the parents. Parents also described how without good management, there are potentially long-term complications such as amputations, blindness and even death. This intensely physical involvement also has psychological and emotional implications. The specific aspects described below delve further into issues of embodiment and the associated difficulties, tensions and complexities of the parents' undertakings as they care for their child with Type 1 diabetes.

Constant Vigilance and Careful Management

Parents described the experience of looking after their child with Type 1 diabetes as being one governed by constant vigilance. Constant vigilance appeared as a manifestation of parental embodiment, and as a response to the embodied constraints experienced by their child due to diabetes. This activity was described as one where "there's never a dull moment", requiring ongoing conscious effort, active engagement and attention on the part of the parents, which can be a "tiring process". This continuous attention had a wide-ranging impact on the lives of those involved. One mother explained the way their family life revolved around diabetes:

Um, it's hard work. It's incredibly hard work. You're conscious all the time, of where she is, who she's with. Is it food time? It is, is she okay? What are her blood sugars? {Int: Mm}. Yeah. Your life tended to revolve very early on around what her blood sugars were. (Participant 2, Mother: Daughter, 12 years).

This vigilance was described as a very active process; more than just awareness, work and attention was required to monitor all aspects of their child's daily life to maintain blood sugar levels. This mother described how when her daughter was first diagnosed at the age of 4 years, everything was recorded; where she attempted to predict the influence of food, activity and insulin on her daughter's blood sugar readings. The blood sugar levels were described as the main driver of the lives of the parents.

Parents employed different strategies to achieve the desired results. Parents needed to plan their child's routines ahead of time, so that different factors such as diet and activity can be taken into consideration when deciding on the insulin dosage. The following account describes the challenge involved with these attempts:

Umm, the hardest thing actually is deciding how much insulin to give her. You know, to plan in advance what she's going to eat and how much exercise she's gonna get...umm...because if you give her too much she's gonna go low...and then ruin the day anyway, or not give her enough and she'll be feeling horrible and hang around you cos she's not feeling very well and...ruin your day like that,

you know, or not ruin but it's sort of a fine line between...yeah. (Participant 1, Mother: Daughter, 5 years).

Planning is seen as necessary, yet any inaccuracy in these attempts will result in blood sugar levels going too high or too low. This reflected the sensitivity of the diabetic body, and the difficulty in predicting the response to food and exercise on any given day. The embodied reaction of the child to the parent's attempts at management has the potential to determine the course and outcome of their day. This mother described the outcome of misjudging the insulin dose not in terms of blood sugar, but in terms of the child either feeling miserable or her behaviour being difficult which can cause difficulty for the parents. The mother's assessment that such inaccuracies can "ruin your day" indicates the pervasive impact of misjudging the insulin dose. However, her notion of a "fine line between" suggests that although this balance is difficult to achieve, it is possible to attain ideal results by having things go according to plan. This mother also described the challenge in achieving ideal results due to her daughter's difficulty with articulating how she was feeling, with the changes in blood sugar levels.

In contrast to this, parents' accounts also indicated that in spite of their best laid plans, they were often faced with unexpected outcomes. Parents attempted to keep diet, activity and insulin doses constant, only to be disappointed with unexpected results. This often left parents mystified and trying to make sense of the process. As one parent commented, "it's really hard to work out where your body is sort of at", referring to the complexities in figuring out the bodily requirements. The unpredictable nature of diabetes made the efforts at managing the disease seem fruitless at times, as described below by one parent:

... a lot of the time it doesn't make sense...ummm... {Int: So not making sense...which ways...}. Like sometimes, we'll give her say 5 units of Actrapid in the morning, and by lunch time she'll be down at 3. With, and this is even at school, when she's doing exactly the same things, eating the same, and then the next day, you give her exactly the same, and she'll be up at 14, and that's what I mean by not making sense, how can you plan for that? Well, you just can't. (Participant 1, Mother: Daughter, 5 years).

Here, the child with Type 1 diabetes is described as embodied within an unpredictable body; bodily certainty has been lost and predictable patterns of input and output have become unreliable. This mother described how her attempts at adjusting insulin doses over several days and even months were often met with disappointment. Even with

careful planning, there is no guarantee that results will be consistent. The reality of caring for children with diabetes is that unpredictability can cast a shadow over parents' attempts at management. Parents spoke about the embodied experience of caregiving in terms of control and surveillance, but attempts at control and consistency were undermined by the inconsistency and variability of outcomes. This unpredictability means that attempts to control the disease process are often fraught, but the nature of the disease means that ceasing management attempts is not viewed as an option. This held true even for families who appeared to struggle in various aspects of their lives, where they were still committed to maintaining good management efforts.

Rather than viewing the attempts at increasingly careful management as impossible, some parents sought more nuanced strategies of management to make sense of this unpredictability. Parents added additional factors into the mix to understand how blood sugars worked for their child, such as incorporating emotion regulation into the framework:

Um, but that's the other thing I've learnt. I always thought it was just food and activity but it's not. It's, there's all the emotional stress and really notice that. You know she'll, she'll have something stressful like starting school and, and it really does throw blood sugars so yeah it's, they're a bit of a guessing game sometimes I think. Yeah. {Int: Hard to predict?}. Yeah. And sometimes you'll take her blood sugar and think how the hang, you're high or you're low but, you know and it just doesn't measure up but there's just something, some other factors that have, yeah. (Participant 12, Mother: Daughter, 5 years).

Rather than viewing the variable blood sugar results as inherently unpredictable, here, this mother attempted to incorporate another aspect of the child's life, emotions, into the process of understanding blood sugar results. The mother described how while her daughter generally being a good eater made it easier for her to manage her diet, the impact of emotions was more difficult to predict. This reflects how the embodiment of the child is more than the mechanistic model of a physical body and incorporates connections between the mind and the body. Whilst acknowledging that it is more difficult to account for emotions than to assess the contribution of food and activity levels, it is viewed as another bodily cue and "another factor" to account for in the management of blood sugar. However, there is still no resolution to the unpredictability, as accounting for emotional regulation is a "guessing game" in a procedural model of input and output based upon food and exercise. Rather than viewing diabetes as inherently unpredictable, it is viewed as subject to a myriad of

additional influential aspects that must be incorporated into the careful management and surveillance of their child. Parenting involves attending to emotional responses and managing situations that might cause disruption. However, parenting a child with Type 1 diabetes has potentially profound physical consequences for emotional reactions.

As well as layering on additional factors, parents also attempted to incorporate individual differences into the model of unpredictability:

...and it's even, like with swimming, when James goes swimming, for us, we know that 8 hours after he's gone swimming, he will go lower. So we have to let him go really high so he has enough to go low. {Int: Yeah}. And so, but that might not be the same for other children so it's very, there's not a standard thing for everyone. (Participant 16, Mother: Son, 11 years).

By integrating individual differences, parents develop a model for each child and thus produce strategies for better management. Again, rather than dispensing with the model of careful management in the face of unpredictable outcomes, the parents focus on increasing sensitivity of their management through careful surveillance of their child's responses and incorporating additional body techniques. Parents may find that the younger the child is at diagnosis, the more sensitivity that they may be able to build into this management. In the case of the mother in the above extract, her son was diagnosed at 4 years. This may have played a role in the parents getting a better understanding of how their son's blood sugar levels worked over time. This demonstrates the level of attention and engagement with their child's body involved in their caregiving role. These individualised approaches to parenting a child with diabetes mean that parents pay even closer attention to their child. This contributes to the parents' experience of never being able to cease their watchfulness, as their child's responses can always be added to accumulated knowledge of managing the diabetes.

Even if the child's diabetes was currently well-managed, parents were aware of the possibility of future unpredictability due to developmental changes. One parent expressed:

So it's just looking forward now, I guess, cos the next hurdle'll be puberty [laugh]. I've heard nightmares, I've heard that that the levels go all over the place, they go absolutely crazy, so I'm not [laugh] looking forward to that. {Int: Yeah, that might take a bit of adjusting to as well...}. [Sigh] That's what I've been warned and I've said that yeah, so we'll just wait [laugh]. (Participant 3, Mother: Daughter, 11 years).

Even in the context of current stability, the notion of future unpredictability is a concern. This was a particular concern for the mother here, as her daughter was a pre-adolescent. Such changes require “a bit of adjusting” as parents live in dread of such changes and how they might undermine carefully mapped strategies of management and surveillance. She described how she hoped the good management practices they had instilled in her would protect her daughter during these changes. This mother attempts to incorporate future unpredictability into established processes, demonstrating that strategies that reduce unpredictability are of vital importance to managing the daily life of living with a child with Type 1 diabetes.

Comparing Diabetes with other Conditions

As a way of dealing with the tensions arising from the embodied experience of parenting a child with Type 1 diabetes, parents used social cognitions located around the body to make sense of their experiences of caring for the diabetic body. Situating their child’s bodily experiences in terms of other possible childhood conditions enabled parents to manage some of the gains and losses of Type 1 diabetes. IPA accords cognition a central role (Eatough & Smith, 2008), and is therefore useful to explore this aspect of the parents’ lived experience. Parents compared parenting a child with diabetes with other possible health conditions or challenges. These comparisons were used in two ways; to compare Type 1 diabetes favourably or unfavourably with other childhood health conditions.

Parents focused on the life that was still possible in the presence of diabetes. Other similar descriptions of diabetes included “it’s actually one of the good ones to get”, “you’ve only got diabetes”, “you’re luckier than many” and “there are a lot worse”. In this manner, parents engaged in a process of social comparison, where they evaluated their child as faring better than many other children with illnesses. By doing so, parents distanced themselves and their children from these other conditions, making themselves feel more in control regarding their situation and enhancing their coping.

Parents highlighted different ways that they deemed their children to be in a better position compared to others. Firstly, the ability of children with diabetes to socially integrate was stressed. One mother touched upon the capacity of children with diabetes to be socially integrated as they are able to “read and to write and have conversations”. She highlighted further aspects that are still possible with diabetes:

And you know the little girl who got meningitis, you know a few years ago, people that had being mauled by dogs and stuff like that, we can watch that and say gosh, isn’t it good that you’ve only got diabetes? And that you don’t have

those things, you can still see, talk and laugh and speak and be active.
(Participant 2, Mother: Daughter, 12 years).

Here, the mother attributes the characteristics of “still see, talk and laugh and speak and be active” as key to a life with opportunities. These are still possible with diabetes. Being able to see, have a conversation and express emotions socially is important to these parents as part of living a full life. Other parents described the ways that diabetes is able to be hidden. One parent recounted:

I said oh yeah aren't you thankful you know your pump's under your top you know you don't, you're not, it's not all on display. (Participant 6, Mother: Son, 9 years).

This ability to conceal diabetes means that children with diabetes avoid the stigmatising effects of more visible chronic conditions of childhood. In this way, the diabetic body is a ‘contained body’, containing ill health and enabling the child to move through the world without apparent signs of illness.

Further comparisons emphasised the ability of children with diabetes to have a normal life span: “she can grow old with diabetes...cystic fibrosis kids don't grow old”. This aspect was further emphasised when diabetes was compared against terminal illnesses such as cancer:

...I mean Cystic Fibrosis they, I mean they die by the time they're 30 so at least he's not dying. That's what I've always thought, you know. It's not, it's not leukaemia so that's sort of a positive. Um, I mean it's, yeah it's not terminal. It's not terminal so, you know you can live with it. (Participant 6, Mother: Son, 9 years).

Here, the mother draws on the temporal element of how bodies function over time. The mother describes how diabetes can be held constant, rather than necessarily deteriorating over time. Even though the diabetic body still can have many future complications, the mother here makes a selective comparison by focusing specifically on the aspect of life-span. The lack of a known time limit or definite end point helps the parents to cope with the disease on an everyday basis as they are able to look towards the possible future.

In addition to this, parents emphasised the manageability of the condition. One parent compared diabetes with another condition where food was also a critical element:

And I said to her, you're lucky because your little friend...she's got a nut allergy, she can't have that food at that party. She will go to the party but she won't have cake, she won't have the lollies, she won't have the chippies in case they are not made in the right place. So we have always just done that, of course we've told Amy that she's lucky that that's all she's got. (Participant 2, Mother: Daughter, 12 years).

Here, diabetes is seen as less serious, and the nut allergy as potentially fatal. By doing so, the mother highlights the flexibility when it comes to what one can eat, and opportunities to deal with the consequences later. With a nut allergy, there is limited freedom in the choice of food that one can enjoy socially, with severe consequences if this is breached. The comparison made here is expressed in terms of 'gratitude' for what is still feasible with a diabetic body.

Parents used their knowledge of how the diabetic body functioned, to demonstrate nuanced differences between the diabetic body and other bodies to enhance their coping processes, and give meaning to their parenting experience. However, this coping style exists with tensions where it competes strongly with comparison processes involving those who are thought to be more fortunate.

In contrast to viewing Type 1 diabetes as a fortunate diagnosis, some parents described diabetes as more challenging to live with than other conditions. Parents used these descriptions to voice some of the challenging aspects of their situation that could not be ignored. Parents described how diabetes is a lifelong chronic condition. One parent provided a comparison with a common childhood scenario of broken bones to demonstrate how diabetes was harder, because of the absence of healing:

Yeah but the, the, the thing as well is that it's forever. You know like that's just his, unless there's a cure, like there was a kid in there that got brought in and he broke his arm, that night, and I remember his mum, cause we were in a ward with, I think there were three other kids. And I remember his mum and you know grandparents coming in and I was, it was terrible at the time but I was thinking, his arm's going to heal. That's just, that's it, you know. But it was just because it was new. (Father: Mm). But that's the thing with diabetes, it doesn't leave. (Father: Doesn't go away). No that's it. It's a life, life-long thing now that he's got to learn to manage. (Participant 13 and 14, Mother and Father: Son, 9 years).

By emphasising how broken bones heal, and comparing this with the lack of healing in diabetes, these parents demonstrate that there is no clear and definite end to the challenges of living with diabetes. For these parents, reflecting on this absence of

healing during the diagnosis process would have been a difficult process, as their son was diagnosed at the young age of 7 years. Healing marks an endpoint and with diabetes this point is never reached.

A similar comparison is made with much more serious illnesses such as cancer. An emotional account by one of the mothers demonstrates the constant grief that comes from the lack of closure in diabetes:

...I don't know maybe it's a good thing if your kid gets cancer cause least in the end they, they die and you grieve and you get over it [tearful]. But... {Int: With diabetes its on-going}. Just oh it's, yeah it's just there's never a break but yeah. It's a tough one. (Participant 6, Mother: Son, 9 years).

In diabetes, there is no clear point at which the parents stop grieving for the loss of the health of the child. In contrast, with a terminal illness such as cancer, perhaps parents have an opportunity for closure either through a cure or through the death of the child. While death itself can be absolutely unthinkable, this mother recognises how at times, this could be preferable to the continuous grief that parents suffer when they have a child with Type 1 diabetes. This account is a poignant reflection of the depth of the impact of Type 1 diabetes. Because children with diabetes have a life-long condition, this means they have a normal life span, but then they also must live their whole life with a chronic condition that has the potential to deteriorate.

Parents also used comparisons with other conditions to depict some of the social implications of diabetes. One parent described the public sympathy that is present with a condition such as cancer, which was viewed as lacking with Type 1 diabetes:

Um, and I don't think people truly understand how hard it is on us on a physical daily, everyday thing. People don't get it. And I think because we are coping and we're fine, people just think oh it must be fine. But it's really hard, and they don't get that. They don't get that, um, whereas if your child had cancer, people'd drop off meals and people would be running round after you, thinking oh you poor things it's terrible, but they're like oh no it's fine. (Participant 5, Mother: Daughter, 9 years).

The limited visibility of the struggles and challenges of Type 1 diabetes acts as a barrier to receiving more understanding and support from the community at large. It is noteworthy that the invisibility of diabetes was considered by parents as an advantage in the earlier comparison, while it is viewed here as a barrier to support. This mother vents the frustration resulting from this lack of understanding of their child's embodied

everyday struggles. This extract also highlights the public presentation of self as a parent of a child with Type 1 diabetes, in how the parent seeks societal confirmation about the difficulty in managing the diabetic body.

Discussion

This study explored the lived experiences of parents of children with Type 1 diabetes, with a particular focus on how they were shaped by embodied dimensions relating to the physical aspects of the child's condition. The first specific aspect of this theme elucidated how a commitment to constant vigilance encompassed parents' continued efforts at understanding and managing the disease. This finding resonates with previous research by Sullivan-Bolyai and colleagues (2003), who also found 'constant vigilance' to be a central theme for mothers caring for young children with Type 1 diabetes. More recently, the concept of 'parallel vigilance' has been proposed (Niedel, Traynor, McKee, & Grey, 2012), which represents the normal watchfulness exhibited by parents alongside a more intense watchfulness for signs of worsening diabetes. In the present paper, constant vigilance is conceptualised as an expression of embodiment within their caregiving role, which arose in response to the intense physical needs of the child. This illuminates how embodiment can be "produced in the presence of and in interaction with embodied others" (Kelly, 2005, p.199). The unpredictability of the diabetic body demanded that the parents engaged in continuous surveillance to ensure the safety and wellbeing of their child. The ramifications of the parents' embodied practices are related to strong imperatives to maintain blood sugar levels to reduce current and long-term risks. Health professionals encourage parents to engage in processes of bodily management to maintain their children's health. Hence, blood sugar levels can be understood by parents as a barometer of the parents' vigilance, creating high expectations of their parenting. Parents may berate and blame themselves when these expectations are not met which could in turn fuel more intense vigilance. Hence, their parental identity is closely tied into these deeply embodied practices of parenting work. Yet the management of childhood diabetes is unpredictable.

The second specific aspect elucidated how parents used social comparison processes as a way of making sense of the diabetic body, which also demonstrated the social implications of parenting a child with Type 1 diabetes. At times parents evaluate and position themselves in a better place compared to other possible health conditions, thereby helping them cope with their situation. Comparisons were made with other children also affected by illness or injury, rather than children with no health problems, making it a comparison located within a certain group of children whose care also

presented challenges to parenting. This type of comparison is termed a 'downward' social comparison in the literature (Buunk, Gibbons, & Reis-Bergen, 1997). Festinger (1954) theorized that people assess their experiences through social comparison with others. In times of uncertainty, when other bases of objective evaluation are lacking, people compare themselves to similar others (Leventhal, Hudson, & Robitaille, 1997). These processes reduce perceived uncertainty. The use of social comparisons was also described by parents of children with Type 1 diabetes in an earlier study (Gannoni & Shute, 2009). Parents made favourable comparisons of their child's difficulties with those experienced by children with physical disabilities. In addition, Gorawara-Bhat, Huang, and Chin (2008) found in their study of older adults with diabetes that 'downward' social comparisons fostered a sense of empowerment for the patients. Social comparison processes are increasingly being explored in studies of health, coping and wellbeing (Buunk et al., 1997).

In the present study, these comparisons mostly drew on the physical and biological aspects of diabetes, with associated psychological and psychosocial implications. A downward comparison can be helpful at times, but does not fully capture the emotional experience of the parents. Parents also justify why diabetes is harder, and in the process, go beyond just a comparison of the physical and biological aspects, and into more of the psychological and psychosocial domains to highlight deeper implications. This comparison provides an opportunity for the parents to acknowledge some of their strong emotional reactions, such as their grief and loss, which they feel compelled to voice. It indicates an underlying need for these difficult experiences to be validated by others. While the downward social comparisons can produce feelings of self-enhancement, the upward social comparisons may reflect feelings of resentment and grief (Arigo, Suls, & Smyth, 2014). Parents may oscillate between these two types of comparisons, or hold these views simultaneously, and one can be more salient over the other at times, depending on circumstances. These two accounts may reflect the unpredictability of diabetes, as parents move between periods where they experience reliable responses to their daily efforts of management and periods where they struggle to maintain good glycaemic control.

The present study's particular strength lies in its in-depth examination of the parental experience through the use of IPA. This allowed for the subtleties and nuances to become more visible, hence contributing to a better understanding of the parents' experiences. The present study also uncovered novel insights into the experience of caring for a child with Type 1 diabetes, such as how the parents make comparisons of the diabetic body to other conditions, and the dialectic in the parents' views that diabetes is easier, and at the same time, harder than certain conditions. In addition,

the study also provided additional insights into the process of 'continuous grief' that parents of children with Type 1 diabetes go through, which has some similarity with the concept of 'chronic sorrow' described by Bowes et al. (2009).

Limitations

A limitation of the current study was the larger number of mothers in the study compared to fathers, consequently the findings may reflect mothers' views. However, this provided a better exploration of diabetic body experiences, as among these participants, mothers generally tended to be in charge of the day to day management of their children's diabetes. Future research could involve more fathers to analyse how gender influences the caregiving experience amongst parents of children with Type 1 diabetes. Parental experiences of looking after a teenager with Type 1 diabetes would also be a worthwhile avenue for further research, paying particular attention to the role of the body. Difficulties of adolescent development can make parenting even more challenging at that time.

The findings of the current study demonstrate the significant impact of caring for a child with Type 1 diabetes on parents. Future research could examine the role of parental self-care on the wellbeing of both parents and children with chronic conditions. While previous qualitative research on diabetes has revealed important elements of the parenting experience, no past research has focused on the specific implications of the diabetic body on the caregiving experience. Using IPA, the present study highlighted the use of social comparisons to understand the experience of parenting a child with Type 1 diabetes. Acknowledging these comparisons and their implications will improve interventions and support by health professionals as they assist families to adjust to life with a child with Type 1 diabetes. Parental experiences impact on the care of the child both directly and indirectly; thus understanding the parental experiences of caring for a child with diabetes is crucial for the wellbeing of both parents and children with Type 1 diabetes.

References

- Arigo, D., Suls, J. M., & Smyth, J. M. (2014). Social comparisons and chronic illness: Research Synthesis and clinical implications. *Health Psychology Review, 8*, 154-214. doi:10.1080/17437199.2011.634572
- Balfe, M. (2009). The body projects of university students with Type 1 diabetes. *Qualitative Health Research, 19*(1), 128-139. doi:10.1177/1049732308328052
- Bowes, S., Lowes, S., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with Type 1 diabetes. *Journal of Advanced Nursing, 65*(5), 992-1000. doi:10.1111/j.1365-2648.2009.04963.x
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, J. A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth. *Diabetes Care, 31*(8), 1516-1520. doi:10.2337/dc07-2349
- Buunk, B. P., Gibbons, F. X., & Reis-Bergen, M. (1997). Social comparison in health and illness: A historical overview. In B. P. Buunk & F. X. Gibbons (Eds.), *Health, coping and well-being: Perspectives from social comparison theory* (pp. 1-23). London: Lawrence Erlbaum Associates.
- Buunk, B. P., Gibbons, F. X., & Visser, A. (2002). The relevance of social comparison processes for prevention and healthcare. *Patient Education and Counseling, 47*, 1-3. Doi:101016/S0738-3991(02)00054-X
- Carel, H. H. (2013). Illness, phenomenology, and philosophical method. *Theoretical Medicine and Bioethics, 34*, 345-357. doi:10.1007/s11017-013-9265-1
- Colls, R., & Hörschelmann, K. (2009). The geographies of children's and young people's bodies. *Children's Geographies, 17*(1), 1-6. doi:10.1080/14733280802630882
- de Boer, I. H., Rue, T. C., Cleary, P. A., Lachin, J. M., Molitch, M. E., Steffes, M. W., . . . Brunzell, J. D. (2011). Long-term renal outcomes of patients with Type 1 diabetes mellitus and microalbuminuria: An analysis of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications cohort. *Archives of Internal Medicine, 171*(5), 412-420. doi:10.1001/archinternmed.2011.16
- DIAMOND Research Group. (2006). Incidence and trends of childhood Type 1 diabetes worldwide 1990–1999. *Diabetic Medicine, 23*(8), 857-866. doi:10.1111/j.1464-5491.2006.01925.x

- Doucet, A. (2006). 'Estrogen-filled worlds': Fathers as primary caregivers and embodiment. *The Sociological Review*, 54(4), 696-716. doi:10.1111/j.1467-954X.2006.00667.x
- Doyle, E. A., & Grey, M. (2010). Diabetes mellitus (types 1 and 2). In P. J. Allen, J. A. Vessey & N. A. Schapiro (Eds.), *Primary care of the child with a chronic condition* (5th ed.). St. Louis, Missouri: Mosby Elsevier.
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). Los Angeles: Sage Publications.
- Falvo, D. R. (2009). Endocrine conditions. *Medical and psychosocial aspects of chronic illness and disability* (4th ed., pp. 333-351). Sudbury, Mass: Jones and Bartlett Publishers.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7(2), 117-140. doi:10.1177/001872675400700202
- Gannoni, A. F., & Shute, R. H. (2009). Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry*, 15(1), 39-53. doi:10.1177/1359104509338432
- Gorawara-Bhat, R., Huang, E., & Chin, M. H. (2008). Communicating with older diabetes patients: Self-management and social comparison. *Patient Education and Counseling*, 72, 411-417. doi:10.1016/j.pec.2008.05.011
- Hatton, D. L., Canam, C., Thorne, S., & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing*, 22(3), 569-577. doi:10.1046/j.1365-2648.1995.22030569.x
- International Diabetes Federation. (2015). *IDF Diabetes Atlas* (7th ed.). Brussels, Belgium: International Diabetes Federation.
- Kelly, S. E. (2005). "A different light": Examining impairment through parent narratives of childhood disability. *Journal of Contemporary Ethnography*, 34(2), 180-205. doi:10.1177/0891241604272065
- Krieger, N. (2004). Embodiment: A conceptual glossary for epidemiology. *Journal of Epidemiology & Community Health*, 59, 350-355. doi:10.1136/jech.2004.024562
- Langdrige, D. (2008). Phenomenology and critical social psychology: Directions and debates in theory and research. *Social and Personality Psychology Compass*, 2(3), 1126-1142. doi:10.1111/j.1751-9004.2008.00114.x

- Leventhal, H., Hudson, S., & Robitaille, C. (1997). Social comparison and health: A process model. In B. P. Buunk & F. X. Gibbons (Eds.), *Health, coping, and well-being: Perspectives from social comparison theory* (pp. 411-432). London: Lawrence Erlbaum Associates.
- Lowes, L., Gregory, J. W., & Lyne, P. (2005). Newly diagnosed childhood diabetes: A psychosocial transition for parents? *Journal of Advanced Nursing*, *50*(3), 253-261. doi:10.1111/j.1365-2648.2005.03388.x
- Lowes, L., Lyne, P., & Gregory, J. W. (2004). Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*, *21*(6), 531-538. doi:10.1111/j.1464-5491.2004.01193.x
- Lupton, D. (2012). Infant embodiment and interembodiment: A review of sociocultural perspectives. *Childhood*, *20*, 37-50. doi:10.1177/0907568212447244
- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Epidemiology of type 1 diabetes. *Endocrinology and Metabolism Clinics of North America*, *30*(3), 481-497. doi: 10.1016/j.ecl.2010.05.011
- Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with Type 1 diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing*, *18*(12), 1703-1710. doi:10.1111/j.1365-2702.2008.02737.x
- Meier, B.P., Schnall, S., Schwarz, N., & Bargh, J. A. (2012). Embodiment in social psychology. *Topics in Cognitive Sciences*, *4*, 705-716. doi:10.1111/j.1756-8765.2012.01212.x
- Montez, J. K., & Karner, T. X. (2005). Understanding the diabetic body-self. *Qualitative Health Research*, *15*(8), 1086-1104. doi:10.1177/1049732305276677
- Nexø, M. A., Watt, T., Cleal, B., Hegedüs, L., Bonnema, S. J., Rasmussen, Å. K., . . . Bjorner, J. B. (2015). Exploring the experiences of people with hypo- and hyperthyroidism. *Qualitative Health Research*, *25*(7), 945-953. doi:10.1177/1049732314554093
- Niedel, S., Traynor, M., McKee, M., & Grey, M. (2012). Parallel vigilance: Parent's dual focus following diagnosis of Type 1 diabetes mellitus in their young child. *Health*, *17*(3), 246-265. doi:10.1177/1363459312451180
- Pop-Busui, R., Low, P. A., Waberski, B. H., Martin, C. L., Albers, J. W., Feldman, E. L., . . . Herman, W. H. (2009). Effects of prior intensive insulin therapy on cardiac autonomic nervous system function in Type 1 diabetes mellitus: The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and

- Complications Study (DCCT/EDIC). *Circulation*, 119(22), 2886-2893. doi:10.1161/CIRCULATIONAHA.108.837369
- Raingruber, B., & Kent, M. (2003). Attending to embodied responses: A way to identify practice-based and human meanings associated with secondary trauma. *Qualitative Health Research*, 13(4), 449-468. doi:10.1177/1049732302250722
- Shulman, R. M., & Daneman, D. (2010). Type 1 diabetes mellitus in childhood. *Medicine*, 38(12), 679-685. doi:10.1016/j.mpmed.2010.09.001
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., . . . Clark, N. (2005). Care of children and adolescents with Type 1 diabetes. *Diabetes Care*, 28(1), 186-212. doi:10.2337/diacare.28.1.186
- Smith, J. A., & Eatough, V. (2006). Interpretative phenomenological analysis. In G. M. Breakwell, S. Hammond, C. Fife-Schaw & J. A. Smith (Eds.), *Research methods in Psychology* (3rd ed., pp. 322-341). London: Sage.
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 35-50). Los Angeles: Sage.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London: Sage.
- Sparud-Lundin, C., Hallström, I., & Erlandsson, L-K. (2013). Challenges, strategies, and gender relations among parents of children recently diagnosed with Type 1 diabetes. *Journal of Family Nursing*, 19, 249-273. doi:10.1177/1074840713484386
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing*, 18(1), 21-29. doi:10.1053/jpdn.2003.4
- Talbot, D. (2013). Early parenting and the urban experience: Risk, community, play and embodiment in an East London neighbourhood. *Children's Geographies*, 11(2), 230-242. doi:10.1080/14733285.2013.779450
- Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7(2), 213-225. doi:10.1348/135910702169457

- Trief, P. M., Sandberg, J., Greenberg, R. P., Graff, K., Castronova, N., Yoon, M., & Weinstock, R. S. (2003). Describing support: A qualitative study of couples living with diabetes. *Families, Systems & Health, 21*(1), 57-67. doi:10.1037/h0089502
- Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: caregiver coping and making sense of illness. *Aging & Mental Health, 18*(5), 600-609. doi:10.1080/13607863.2013.860425
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Philadelphia: Open University Press.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215-228. doi:10.1080/08870440008400302
- Zimmet, P., Alberti, K. G. M. M., & Shaw, J. (2001). Global and societal implications of the diabetes epidemic. *Nature, 414*, 782-787. doi:10.1038/414782a



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**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

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The Parental Experience of Caring for a Child with Type 1 Diabetes: Issues of Embodiment

In which Chapter is the Published Work: Chapter 3

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or

- Describe the contribution that the candidate has made to the Published Work:

The candidate is responsible for the analysis and write-up of the manuscript. The supervisors contributed to the manuscript by providing guidance on structuring arguments and the clarity of the write-up.

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CHAPTER 4: BIOGRAPHICAL DISRUPTION AND THE PURSUIT OF NORMALITY IN THE PARENTAL EXPERIENCE OF CARING FOR A CHILD WITH TYPE 1 DIABETES

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Abstract

Parents of children with Type 1 diabetes are responsible for carrying out a complex treatment regimen on a daily basis. Parents can experience significant stress and worry as they adjust to this additional caretaking responsibility. There is a limited body of research on the parental experience of the transition to caring for a child with Type 1 diabetes. This paper uses Interpretative Phenomenological Analysis (IPA) to explore this transition in interviews with 17 parents with children with Type 1 diabetes. Parents experienced a profound biographical disruption from the moment their child was diagnosed. This undermined their confidence in the ability to take care of their child. Parents likened this to the experience of having a new baby. Several repair structures worked to reconstruct parental identity, centered around the idea of normality. These involved normality through typical childhood experiences, embracing a new normality, and preserving family normality. These findings highlight the profound impact of the diagnosis on parental identity. Recognising the significant and far-reaching disruption in parental identity that a diagnosis of Type 1 diabetes in a child causes will enable health professionals to provide more support in making sense of this change in the parents' lives.

Introduction

Type 1 diabetes mellitus is one of the most common chronic diseases of childhood (Atkinson, Eisenbarth, & Michels, 2014). It is associated with several short and long-term health risks. Treatment involves a regimen of insulin therapy, management of diet and activity levels, and glucose monitoring with the aim of maintaining blood glucose levels within normal limits (Doyle & Grey, 2010). The maintenance of normal blood glucose levels with intensive therapy has been shown to delay the onset and slow down the progression of diabetes-related complications, such as nerve damage, blindness and amputations (de Boer et al., 2011; Pop-Busui et al., 2009). As this can be a complex process, parents and caregivers of children with Type 1 diabetes tend to be heavily involved in the daily management of the disease. Understanding the experiences of parents can thus inform better support for both the child and parents.

Much of the existing research on the psychological experience of parents of children with Type 1 diabetes have been predominantly quantitative, focusing primarily on aspects such as impact of the diagnosis, parental stress, and adjustment (e.g., Hilliard, Monaghan, Cogen, & Streisand, 2011; Jönsson, Lundqvist, Tiberg, & Hallström, 2015; Moreira, Frontini, Bullinger, & Canavarro, 2014). The findings of these questionnaire-based studies mainly point to negative outcomes, such as lower health related quality of life as a result of caring for a child with Type 1 diabetes. This research provides little insight into the unique experiences of parents as they adjust to the diagnosis. Consequentially, a growing body of qualitative literature has examined this experience. This literature has explored themes of grief and loss, stress and worry, and constant vigilance, in describing the impact of the diagnosis on the parents and their experiences of negotiating transitions (Buckloh et al., 2008; Lowes, Lyne, & Gregory, 2004; Marshall et al., 2009; Smaldone & Ritholz, 2011; Sullivan-Bolyai, Deatrck, Gruppuso, Tamborlane, & Grey, 2003; Whittemore, Jaser, Chao, Jang, & Grey, 2012). The current research aimed to extend this literature by exploring the experiences of parents as they transition to caring for a child with Type 1 diabetes, paying particular attention to the psychosocial processes that underpin their experiences.

Chronic Illness as Biographical Disruption

The present article discusses elements of biographical disruption that arose for the parents in the current study following the diagnosis of Type 1 diabetes in their child. Biographical disruption is a key concept in the sociological literature on chronic illness. First described by Bury (1982), it refers to the disruption of taken-for-granted assumptions and behaviours, and to changes in biography, self-concept and resources subsequent to an illness diagnosis. Bury analysed the experiences of people with newly

diagnosed rheumatoid arthritis to describe this process. Bury elucidated how the illness disrupted structures of everyday life, expectations and plans for the future, resulting in “a fundamental rethinking of the person’s biography and self-concept”, leading to a mobilisation of resources to deal with the disruption (1982, p.169). The concept of biographical disruption thus provides a way of shedding light on the effect of an illness diagnosis and trajectory on a person’s life. In this way, the meaning of chronic illness is viewed within the temporal and life-course context (Bury, 1997). Two types of meaning have been described to follow the disruptive event (Bury, 1988). Meaning as consequences emphasise the practical problems and social issues that arise as a result of the chronic illness, while meaning as significance describe the connotations carried by chronic illnesses, such as fears about stigma or discrimination (Bury, 1988). Exploring these meanings can reveal more specific implications such as the deeper significance of a chronic illness on an individual’s identity (Bury, 1997).

Consequently, biographical disruption has been used to describe the effects of chronic illness on individuals’ identity. Ashbring (2001) studied biographical disruption in women with chronic fatigue syndrome and fibromyalgia and found that they experienced an identity loss in relation to work and social life, and engaged in a process of re-evaluating their former identity. Dickson, Allan, and O’carrol (2008) found that a sense of inadequacy and insignificance characterised the impact on the identity of the participants following a spinal cord injury. Similarly, Wilson (2007) examined the relationships between a key identity, motherhood, and living with HIV infection. The women in this study worked hard at establishing and maintaining an identity as good mothers in the context of this stigmatising illness. Hence, the concept of biographical disruption allows for an exploration of the implications of chronic illness on individuals’ identities, and highlights the significance of restructuring meaning during illness, providing a useful way of understanding the experience of chronic illness (Kralik, Visentin, & Van Loon, 2006),

In spite of the popularity of the concept within the chronic illness literature, the exploration of this concept within caregivers’ experience of chronic illness is much more limited. Young and colleagues (2002) explored biographical disruption in mothers of children with cancer. Mothers were described as undergoing biographical disruption, where “being the mother of a child in crisis required a fundamental redefining of mothers’ self-identities and the work of motherhood” (Young, Dixon-Woods, Findlay, & Heney, 2002, p.1837). The mothers took on new responsibilities and obligations, such as an obligation of constant proximity, and carried out additional emotional work, which then had consequences for their self-identity. Harden (2005) discussed several dimensions of parental responsibility that appeared in parents’

narratives in caring for children with mental health problems, to demonstrate the consequences on their parental identity. Similarly, Todd and Jones (2005) described the identity-loss that occurred for parents caring for children with intellectual disabilities. Hence, examining the biographical disruption that may occur for parents following the diagnosis of a chronic condition in a child can allow for an exploration of the relationships between parental identity and parents' experiences of caregiving.

This paper will discuss the biographical disruption that became evident in the parents' descriptions of their transition to caring for their child with Type 1 diabetes and how they dealt with this disruption. It provided an opportunity to examine the radical changes that took place in the parents' lives during the process of adjusting to their new responsibilities. This study used Interpretative Phenomenological Analysis (IPA) as the research method, which facilitated an in-depth analysis of the parents' accounts.

Method

Participants

Participants in this study were parents of children aged between four and twelve years who had been diagnosed with Type 1 diabetes for a minimum of six months. Participants were recruited from three main district health services that provide specialist care for people with diabetes in New Zealand. An information sheet for the study was mailed out to the families in their database meeting the study criteria. Parents interested in taking part in the study contacted the researcher. A total of 17 parents (14 mothers and three fathers) were interviewed before data saturation had occurred. While the study information sheet invited both parents to participate, in the majority of families, mothers volunteered to take part. Both parents were interviewed at the same time in two interviews. One participant had two children diagnosed with Type 1 diabetes, with the younger child's age within the inclusion range. Table 1 summarises the participant characteristics.

Procedure

The present study involved in-depth semi-structured interviews, conducted by the first author. With the exception of one interview, all other interviews were carried out at the parents' own homes. An interview schedule with open-ended questions was used as a general framework to guide the discussion, while allowing flexibility for parents to tell their story in their own words. The schedule began with general questions such as "Tell me about when you found out that your child had diabetes", to allow the parent to describe the diagnostic process and facilitate rapport. More focused and sensitive

questions were then asked, such as “What was the hardest part about it?”, “What worries you the most about your child having diabetes?”, to tap into the challenges they faced in their transition in caring, and “How have you come to terms with your child having diabetes?”, and “What have you found helpful for coping?”, to allow parents to describe their experiences of adjustment and coping. The interviews lasted between 45 minutes to two hours. Interviews were digitally recorded and transcribed verbatim by a professional transcriber. The transcripts were reviewed for accuracy by the first author. A copy of the transcript was made available to those who requested it. Data collection occurred between May 2012 and November 2012. Ethical approval was granted by the Central Regional Ethics Committee of the Health and Disability Ethics Committees.

Table 1

Demographic Characteristics of Participants and their Children

| | <i>N</i> | Mean | Range |
|-------------------------------|----------|------|----------|
| Parents | 17 | | |
| Parental age (years) | | 40 | 28-54 |
| Relationship to child | | | |
| Mother | 14 | | |
| Father | 3 | | |
| Ethnicity | | | |
| New Zealand European | 15 | | |
| New Zealand Māori | 1 | | |
| Other European | 1 | | |
| Relationship status | | | |
| Married/cohabiting | 13 | | |
| Separated/divorced | 4 | | |
| Employment | | | |
| In paid employment | 9 | | |
| Not in paid employment | 8 | | |
| Children | 15 | | |
| Child’s age (years) | | 9 | 5-12 |
| Child’s gender | | | |
| Female | 8 | | |
| Male | 7 | | |
| Age at diagnosis (years) | | 4.50 | 1.16- 10 |
| Duration of diagnosis (years) | | 4 | 0.75-9.5 |

Data Analysis

IPA was chosen as the method of analysis for this research to enable an in-depth examination of the lived experiences of parents who have a child diagnosed with Type 1 diabetes. IPA commits to examining individuals’ lived experiences in detail and understanding how individuals make sense of those experiences (Eatough & Smith, 2008). The term ‘lived experience’ has been used by researchers to represent the

embodied, socio-culturally and historically situated person present in an intentionally interpreted and meaningfully lived world (Eatough & Smith, 2008). IPA addresses different aspects of this lived experience, ranging from individual's wishes, desires, feelings, motivations, and belief systems through to how these are translated into behaviour and action (Eatough & Smith, 2008). IPA also draws from a symbolic interactionist perspective. Symbolic interactionism emphasises the importance of symbols and the interpretative processes that maintain interactions as fundamental to understanding human behaviour (Patton, 2002). Human beings are seen as creative agents who construct their social worlds through their inter-subjective interpretative activity (Eatough & Smith, 2008). A symbolic interactionist perspective allows for an exploration of the changes in self-concept throughout a person's life (Charmaz, 1983). IPA is also useful for exploring process. Rich information about the *process* of adjustment can be provided by IPA (Thompson, Kent, & Smith, 2002), in contrast to methods that may emphasise adjustment *outcomes*.

Data analysis was commenced after the completion of all interviews. The interview transcripts were analysed using IPA by following the steps described by Smith and Osborn (2008). The first stage involved becoming familiar with the transcript and noting down initial thoughts and observations on the margin of the page. Next, emerging themes were noted down on the side of the page with initial notes transformed into more specific themes (Smith & Eatough, 2006). Themes were then clustered by connecting them together, capturing the main categories of meaning conveyed by the participants (Willig, 2001). A descriptive label was given to each cluster to express the conceptual nature of the themes involved (Smith & Eatough, 2007). Finally, a summary of the higher-order themes was developed. The next stage involved closely examining the most salient higher-order themes. Once a theme was selected for further analysis, the transcripts were examined again to select the extracts coded under the theme, copying them into a new word-processed file. Each individual extract was then analysed and coded. Themes were then formed from closely related codes. The final stage involved transforming this structure of themes into the write-up of results. This paper presents two inter-related themes that were identified from this process of analysis, "A new baby: A transitional moment" and "In pursuit of normality".

The rigor and trustworthiness of the current study was ensured by considering the guidelines for evaluating qualitative research suggested by Yardley (2000). The transcripts were read multiple times alongside the developing themes, to ensure that the themes were grounded in the data. While all transcripts were analysed in detail by the first author, all authors were involved in the development, mapping and refining of

themes to ensure the reliability of the final account. The transparency of the study was supported by describing the research sample, settings and procedures in detail. Reflexivity ensured a consideration of the researcher's characteristics on the research process and outcome (Berger, 2015). In the reporting of the results of the study, the selected extracts were edited to ensure confidentiality. All personal and identifying information were removed and pseudonyms placed where people's names appear. The interviewer's questions and comments appear within brackets { }. Observations during the interview, such as pauses and participant reactions (such as laughter) are indicated inside square brackets [].

Results

Parental accounts highlighted how the impact of the diagnosis of Type 1 diabetes in their child encompassed all areas of their lives. Parents attempted to make sense of this disruption by reflecting on causes or explanations for their difficulties, and by mobilising resources to deal with the disruption, consistent with features of biographical disruption (Bury, 1982). A diagnosis of Type 1 diabetes in their child had a significant impact on their parental identity. Parents described the biographical shift that they experienced with the diagnosis by drawing parallels with another major life transition- becoming a parent. This is explored under the theme "A new baby: A transitional moment", which presents the ways that parental identity was challenged. The theme "In pursuit of normality" describes how parents sought to resolve this biographical disruption and regain a sense of 'normal' family life.

A "New Baby": A Transitional Moment

Several parents used the analogy of having a new baby to describe their transition to having a child diagnosed with Type 1 diabetes. Parents drew similarities between the experiences of having a new child and having a child diagnosed with diabetes, highlighting both of these moments as significant and overwhelming. They represent transitional life changing moments marked by new responsibilities and changed expectations. In both situations, parents are engaged in a process of getting to know and understand their new child. Parents explained their experience in this way in an attempt to anchor it to something that they have previously experienced and to an experience that many people (including the interviewer) can relate to. The use of this analogy might also indicate the difficulty in parents expressing their experiences to others, in how parents felt that a metaphor was needed to convey their experiences. The analysis of parental accounts highlights the similarities between the two events, and also brings into sharp relief the differences between the two, emphasising the

chronicity of the condition. These accounts demonstrate the ways their parental identity was ruptured.

Parents described how this “new baby” experience commenced from the moment that the child was diagnosed as having Type 1 diabetes, usually at the hospital. One mother, whose daughter was diagnosed at the age of 4 years, drew on the parallel in the sense of responsibility between the two events:

{Int: So what was the hardest part about it?}. Umm, the fear of being responsible for her life. A little bit like when you brought your baby home for the very first time, you are suddenly responsible for this human being, this life, it's up to you to keep this child alive, that was huge. That was amazingly huge, that when we went out ... umm her blood sugars were 19 at one stage and I went into a panic, just all out panic, I just bundled her up, took her straight back to the hospital. Because I wanted to be where somebody else was in charge. (Participant 2, Mother: Daughter, 12 years).

A diagnosis of diabetes marked their transition from being a parent of a ‘healthy’ child, to parents of a child with a chronic illness. The child is no longer the robust child they had become accustomed to parenting, but is again the fragile newborn. In this way, the diagnosis returned the parents to the uncertainty experienced when caring for an infant, challenging their established parental identity. The mother portrayed the innate protective instinct that comes with having a newborn child by her description of “bundled her up”. This is something people describe doing with a new born that is mirrored here. The realisation that the child’s survival is entirely dependent on the parents’ caring translated into the fear and panic that came with attending to her needs. By the mother “wanting to be where somebody else was in charge”, she questions her ability to undertake the immense responsibility of taking care of her child with diabetes. In this way, the diagnosis of Type 1 diabetes disrupted the confidence in ability to parent and respond to the needs of her child, inherent in the established parental identity. The parent had further described how the loss of confidence was made worse by the fact that she felt total responsibility for her daughters’ care, being her mother.

This appraisal of parenting capability can lead to feelings of inadequacy and insecurity in parents. One parent, whose daughter was diagnosed at the age of 8 years, highlighted the similarity in how these feelings are invoked on taking home your first child and taking home your child with diabetes:

We went into town and we took Maya with us and we were like, we were really scared [laughs] cause we didn't know what to do with her... and I remember one of the nurses saying to me it's like bringing home a new baby all over again. That's exactly how it felt. It was like, all of a sudden, I remember when we left the hospital with our first baby, I remember saying to [husband] I don't know what to do with him. You know like what do I do, what will I do if it wakes up, what will I do if it cries, you know I was like oh. And it felt like that with Maya. (Participant 5, Mother: Daughter, 9 years).

Feelings rooted in uncertainty resurface once again for parents when taking home a child with diabetes, as they are faced with parenting a new child with novel and different developmental needs, from the child they brought home from the hospital the first time. While the experience of uncertainty can be normal with a new born baby, it is an unexpected and unsettling response in the parenting of an older child. This mother further described this experience as causing her to pretend that everything was 'normal' on the outside. This may demonstrate how parents may view feelings of inadequacy in parenting as a threat to their established parental identity.

A further threat to their parental identity was apparent in how diabetes had challenged the confidence that these parents have in their ability to see their child through the natural progression of life. Fears of sugar levels going low in the night were always present, which could result in the child going into a coma or even dying:

You know I mean I used to just worry if, honestly used to worry that he wouldn't be alive when I woke up in the night, you know, and I would check to see if he was moving or breathing... I'd always be scared, every night there's the stress of what's it going to be. ... we've had some scary times when he's had seizures and stuff from going low and, and there's so many times you just look at him and you think he can't, when he gets into that state at night he can't help himself. If I wasn't there he would die presumably. (Participant 8, Mother: Son, 12 years).

These fears mirror the fears that some parents have around cot death with a new born, that the child could die at night unless parents kept close watch. This nightly attending can be episodic and longer for parents with Type 1 diabetes, whereas with a new baby the activity could be expected to lessen as the baby gets older. These fears compromise the taken-for-granted confidence that parents have previously developed that their child is safe. Diabetes has challenged the very foundations on which parental identity is based on by destabilising this confidence. For the mother in the above extract, the loss of confidence may have been felt more strongly, and for much longer,

as the child was diagnosed at the early age of 2 years. Her nightly fears may also have been amplified as she was a single parent, taking full responsibility for her child.

A further rupture in parental identity can be observed in the loss of parental independence that follows the diagnosis of diabetes in a child. One mother described this loss in terms of how diabetes “holds up life”. Some parents gave up their employment, or changed to part-time work after the diagnosis to take on the new responsibilities. One mother gave the following account:

... you know I can't just go out to work and feel that he's safe. I know people do it, and I don't know whether he is more brittle than others, whether it's because of his tummy that it's made it more difficult to manage. Um, but I wouldn't feel I was doing him justice by putting him into someone else's hands with, well he's got other conditions as well but you know ...it's harder. (Participant 8, Mother: Son, 12 years).

This mother describes the felt obligation to prioritise her son's needs, in order to ensure better health for his future. In this process, employment becomes untenable given the demands of parenting a child with such an illness. For this mother, additional health conditions in the child increase the pressures related to caregiving. Parents also described how their social life dwindled since the diagnosis, demonstrating how the disruption demanded a more immediate focus on family life. One mother, whose daughter had been diagnosed 3 years previously commented “me and [husband], we do stuff with the kids...we never go out at night... ever since Clair was diagnosed, we haven't been out”. These point to the ways that the diagnosis had made their lives smaller, and more restricted. However, some parents described increased freedom with time, as their children took more responsibility for their diabetes management.

Parents used the analogy of having a new baby to describe the experience following their child's diagnosis of Type 1 diabetes. The biographical disruption that ensued undermined their existing parental identity by challenging their parental confidence and independence. A new identity emerged which was being a parent of a child with Type 1 diabetes. This new identity involves additional roles such as being a nurse, an educator and an advocate for the child, demanding even more parental effort. Parents were faced with accommodating these novel needs into their lives, as they adapted to caring for their child with the chronic condition.

In Pursuit of Normality

One key way that parents sought to manage and resolve the significant biographical disruption was by attempting to maintain or re-establish a sense of normality in their lives. By doing so, parents sought to adjust to the change rather than resist it. Bury (1991) suggests that normalisation in the face of disruption can be a form of coping with illness, involving a psychological 'bracketing off' of the impact of illness so as to minimise its effect on identity. One parent described "normality is the easiest, easiest way", of coping with the condition. Different repair structures using the concept of normality were used by the parents, demonstrating how multiple meanings of normality can exist for these families.

To begin with, parents' talk indicated an acknowledgement of the loss of normality for their child with Type 1 diabetes. A diagnosis of diabetes immediately restricted the sort of childhood that the child could have. Parents described how diabetes compromised a child's carefree nature and freedom, and how it contributed to a loss of spontaneity in their lives. The child can no longer be spontaneous, as doing things with an absence of planning would not be serve in the best interest of diabetes management. This loss of flexibility and autonomy was clearly felt by the parents as a key aspect of childhood that was taken away by diabetes. One mother gave the following account to describe the normality that was lost for her son with diabetes:

... I mean if he was a normal 9 year old I'd let him go out the back of the farm to the bush out there cause he's a real out-doorsie kid, but I won't let him go out there cause if he was out there and he was low, I couldn't hear him, I mean like least here he's on the roadside that if he fell out of the tree there's, there'd be somebody going past, you know there's, and if he wasn't back within 20 minutes or something. (Participant 6, Mother: Son, 9 years).

The mother's reluctance to let her son explore the outdoors on his own, where there was no close supervision is understandable due to the very nature and the unpredictability of the illness. This protective behaviour however inhibits the child's explorations and enjoyment through play. For the mother in the above extract, the loss of normality of her son's childhood may have been felt for longer, as the child was diagnosed at the young age of 2 years. Parents also talked about some of the added elements in the child's life that other children are not burdened with, such as making "adult" choices. Children with diabetes face a level of responsibility beyond their age, and have the pressure of making good choices now to ensure access to a secure future. These children were no longer able to just live in the now and enjoy spontaneous adventures, without having to think about their actions and

consequences that would impact on their future health. One parent, whose son with diabetes was 8 years old, described that “children shouldn’t have to think about the bigger picture out there”, but this has been severely disrupted by diabetes, as children face ever growing responsibility for their own future wellbeing.

Regardless of this loss of envisioned normality for their children, parents were still committed to ensuring that children achieve some version of normality through typical childhood experiences. These involved activities such as eating lollies, and attending birthday parties or sleep-overs. Parents make a quiet rebellion against diabetes when letting their children enjoy such experiences and still have fun, as this meant that they had to manage certain threats to diabetes management. Reasserting normality in this way involved a high level of effort, planning, flexibility and compromise on the part of the parents, indicating the complexities of the negotiations involved, as evident in the following extract:

...couple or three weeks after being diagnosed she was invited to a birthday ... And she was upset because won't be able to eat anything, I said yes of course you can, you can have cake, you can have lollies you can have biscuits, but you'll just get a smaller piece of cake, and because you're 4 you can have 4 lollies and we worked it out and we catered for her afterwards and I did say to her, unfortunately cos the thing is that if you do have this party food, there's a chance that you might need another injection in the afternoon. But she was prepared to do that because she wanted the party food. (Participant 2, Mother: Daughter, 12 years).

By working around the treatment regimen and by being flexible, the mother was able to let her daughter aged 4 years still be part of the experience of attending a birthday party. She further described how the ability to adjust insulin injections reflected the flexibility that can be exercised to some degree with diabetes, while comparing it to unnegotiable conditions such as a food allergy. Several parents described using insulin injections in this way as a ‘prop’, in helping their child enjoy this key childhood activity. Parents went beyond the immediate management of the child’s diabetes to accommodate diabetes into their child’s life and reassert a sense of normality.

Parents also stressed why they perceived their children’s participation in these vital childhood experiences as crucial. One parent, whose son with diabetes was 7 years old, described the importance of continued participation in these activities helping with the child’s social integration: “well it’s important that your child... feels that he can be part of everything else”. The parent emphasised why not letting the child miss

out on experiences that other children have access to helps the child fit in and be like everyone else.

A normal childhood involves not just access to friends and parties, but also discipline. Parents adhered to the ideal of a normal childhood by attempting to maintain usual disciplining protocols. This involved not giving the child any special treatment or letting them get away with any undesired behaviour due to the fact that they have Type 1 diabetes. To achieve this, parents need to differentiate between diabetes-related behaviour and other age-appropriate behaviour, as described by the following account:

Keeping things normal for him is the most difficult thing because most other adults in his life can't help but, I reckon, can't help but feel sorry for him and it, and it, I think it affects him negatively if people let him get away with stuff because he's less fortunate or something.... Ah, I try and remind people that are taking care of him when I'm not around that um a lot of his behaviour is actually just a normal five year olds' behaviour and to remember sometimes it's actually, it's actually not a high or a low or a um, not feeling well or anything like that. It's actually just normal 5 year old behaviour and he needs to be just you know same rules apply for him to everyone else. (Participant 9, Mother: Son, 5 years).

By being aware that some of her son's behaviour can be typical and age-appropriate, this mother describes how she can continue to approach discipline as she would with any other child. In this way, the perception of normality is maintained by the parents. This account also highlights the difficulty in maintaining this desired state of normality when others are involved in the child's care, as their interpretation of the child's behaviour can be different to the parents'. The mother in the above extract described how being a single mother, she needed to rely on several others to care for her son, to enable her to work full time. Parents' accounts also indicate the additional effort needed to differentiate between child moodiness that is age appropriate and that which could be stemming from a high or low blood sugar reading, demonstrating the additional work involved for them.

Another parent described the way she came to conceptualise the diabetic version of child moodiness which helped her to understand her daughter's diabetes related misbehaviour: "Sometimes she's Maya and sometimes she's diabetic Maya. And they're quite different people and the handling them is quite different too so, that's been good for me to work out that split". Through the objectifying of diabetes, the mother attempts to separate the impact of the diabetes on her 9 year old daughter's

demeanour, thereby helping them interpret her behaviour and attend to it accordingly. This reconceptualization further demonstrates how maintaining normality through disciplining involves additional complexities faced by parents with children with Type 1 diabetes. Parents are committed to the ideal of a normal childhood as parental identity strongly hinges on the sort of childhood that parents provide for their children. By still being able to provide the child with similar childhood experiences as their peers, including similar disciplining, parents restore the identity disruption caused by diabetes.

In addition to the efforts at maintaining normality through normal childhood experiences, some parents incorporated ways of pursuing normality that worked to ultimately redefine what normality meant for these families. These efforts at redefining normality involved setting a family's version of normal that would accommodate the child's new normality; the diabetes. Parents' notion of a 'different normality' indicates a recognition of this new normality being different from what it was before, and different to other families. In the following account, one mother describes how her daughter's new normality was incorporated into their family's interpretation of normal:

Yeah, just normal... part of her normal day, part of her normal routine, and the normal conversation that we have you know, have you done your numbers, you know it's part of what is, what goes on in this house, that's, you know some people might say, have you been for your run this morning, or something like that but our conversation in our house in any given day you know, have you done your numbers or did you bolus for that or you know, that's again she, other kids would never have heard of that, but that's what's normal for her so, that's what's normal for us ... You know cos again that's that's the normality of it so, maybe slightly different to the average household. (Participant 4, Mother: Daughter, 11 years).

Here, the mother depicts how her daughter's normality of living with her diabetic needs have been extended to inform the family's version of normal. The mother indicates how embracing this different normality allows them to cope better with the condition. She added how they had made sought to make diabetes a normal part of their lives, right from the start when her daughter was diagnosed at 4 years, due to the critical nature of diabetes. This version of normality helps to minimise the differences of the child with diabetes from other members of the family which makes them appear more normal within the family unit.

Parents' talk indicated how a redefinition of the family's normal involved many changes, such as changes to family routines and family rules, indicating their willingness to alter important facets of family functioning:

Um, when it comes to what Thomas can and can't have well John just follows, he does the same thing. Like if Thomas has a low and gets to have a couple of jelly beans well that, that's when John gets his jelly beans too you know it's, no point in trying to give one lollies when the other can't have any. Um, [short pause] if Thomas can't have something it's, the answer's no and it's no for both of them. It's no for everyone. (Participant 9, Mother: Son, 5 years).

Redefining normality involved realigning family life to what was normal for the child. Having the same rules apply for both children helps the family in its overall organisation. This may be true especially for families with children who are close in age, such as for the mother in the above extract. The family can gain more stability as a result with less disruption as the whole family abides by this one set of rules. More importantly, underpinning this attempt at redefining normality is the parent's endorsement of fairness for her son with diabetes; it's not fair for the other son to enjoy something that her son with diabetes cannot have. Fairness is a key value that the parent is keen to preserve, especially when getting diagnosed with Type 1 diabetes, has been an unfair event to begin with. On the flipside, it can also be argued that it can be an unjust transaction for the other son, who does not have diabetes, as some of his freedom within the family can be compromised. One parent described how she addresses this aspect of unfairness for the child without diabetes, by taking him out on special treats:

..the idea of doing separate meals was not something that I took to at all. Everything changed for all of us so in that respect I think that um you know Charlie [child without diabetes] hasn't been um left out or um I, I take him, we have um, we have dates where I take him and we do something special ...So we can go to the café and just have you know hot chocolate and marshmallows um, and not feel guilty. (Participant 10, Mother: Son, 8 years).

Here, the mother assuages her feelings about all members of the family eating a diabetic diet, by providing opportunities for the child without diabetes to have non-diabetic experiences. The mother described how her son without diabetes, similar in age to the child with diabetes, had to be tolerant of what went on in their 'diabetic' household, and may have felt this child deserved these different experiences. In this

way, the mother attempts to repair the normality for the child without diabetes in the family, as their normality is also challenged in addition to the child with diabetes.

Parents also spoke about their new normality being supported through interactions with similar others, such as other parents of children with Type 1 diabetes. This involved parents and children connecting with others through their participation in activities such as diabetes camps, social events and support group meetings organised by the local diabetes support agencies, or even by reading about other's experiences through different media sources. One parent emphasised the key role of shared experience in obtaining this sense of normality:

I think shared experience is probably one of the best things to make you feel normal and to realise that you're not alone. Cause otherwise there's a lot of nothing being normal. (Participant 5, Mother: Daughter, 9 years).

This mother highlights the powerful way that shared experiences can help validate the parents' experiences and deal with the feeling of isolation that often results. This mother also described the reassurance that came from meeting an adult with Type 1 diabetes, soon after her daughter's diagnosis, in seeing how normal and healthy she looked. Parents come to appreciate that their situations aren't unique and a lot of their experiences are mirrored in others' situations as well.

Adhering to the idea of a new normality shows how diabetes has shifted the whole family in adjusting to the child's needs. Parents' adherence to this new normality may repair the disruption to their identity as good parents, by accommodating the needs of the child with diabetes in routines the whole family shares.

In contrast to redefining normality by changing the family's version of normal, parents also described their feelings towards not letting diabetes define the way they operated as a family. In this respect, for some families, and in some circumstances, diabetes did not become their new normal. Instead they worked to preserve the existing normality of the family. Here, the persistence of normal was perceived as essential not just for the sake of the child with diabetes, but also for the functioning of the entire family. One parent describes how they contended to maintain their family's normality:

...ours is just normal. We're just a normal family. Yeah. Yeah there's nothing we don't do because of it so yeah. Yeah ...it just shapes the way you do things a bit more but ... yeah it's just something that's happened that you just make part of your life and then just, yeah just add it into the mix really and then work with it, yeah. Yeah. Cause it doesn't, it doesn't need to stop us from doing anything. You

just need to think about it a bit more before you do it sort of thing. (Participant 12, Mother: Daughter, 5 years).

This strive for family normality involves extra effort. Additional thinking and planning is a prerequisite in not allowing diabetes to limit their family life. But this is deemed necessary to ensure that families can continue to enjoy the same activities and routines they would have in the absence of diabetes. For the mother in the above extract, family meant “everything”, where she took pride in enjoying each other’s company through various family activities. An understanding that their family identity had not changed due to diabetes can be reassuring to parents. One mother commented “being regimented really into eating at certain times, which I mean to some degree we do..umm...but I’m not strict strict on...cos we’ve got to live as a family too”. She emphasised the need to balance family needs with diabetic needs in maintaining family normality. By not giving into the diabetic needs completely, family freedom is still maintained to some extent. Diabetes is made to fit into the existing family routines and systems.

Discussion

This paper has presented two themes that allowed a closer look at parents’ lived experiences of transition in caring for a child with Type 1 diabetes. Describing how the parents experienced biographical disruption highlighted the wide-ranging impact of the diagnosis on the parents’ lives and the strategies that parents use to restore a sense of normality following diagnosis. This contributes to an enhanced understanding of the social processes that operate within the context of care-taking, such as the reflexive constructions of their parenting role and role obligations (Young et al., 2002). Such knowledge can help identify key issues and challenges that parents face in caring for their ill children that are under-recognised.

Parents used their past familiar experience of having a new baby, which is a normal transition, to locate their current unexpected transition of having a child with Type 1 diabetes. For these parents, the diagnosis stories appear as a kind of rebirth of a new baby, where parents are given a new child, who has different and often frightening needs. Parents’ accounts carry a notion of being thrown back to the beginning of their parenting career, where disrupted sleep patterns, lack of confidence, and uncertainty prevails. For these parents, the “new baby” stage does not have an apparent end. The disruption posed threats to their existing parental identity. An impact on parental confidence and a loss of independence were key features of their accounts. Similar findings were reported by Marshall and colleagues (2005), in that parents of children

with Type 1 diabetes described a loss of their own freedom and confidence in parenting.

These findings support that parents experienced biographical disruption due to the Type 1 diagnosis in their child. Biographical disruption may be one way of conceptualising the impact of chronic illness. Williams (2000) has reflected upon the usefulness of the biographical concept in attending to the diversity in illness and disability experiences. Since the original idea, further concepts have been explained such as biographical reinforcement in HIV-positive men (Carricaburu & Pierret, 1995) and biographical disintegration in the case of childhood suicide (Owens, Lambert, Lloyd, & Donovan, 2008).

The findings presented in the second theme delved into how parents sought to repair the biographical shift by embracing the idea of normality. Normality is comforting, as it reminds parents that even after the huge disruption caused by the diagnosis of the chronic illness in their child, not everything had to change. Preserving normality appeared to be a difficult task in the context of balancing these efforts with the diabetic needs.

Concepts of normality have been described in other studies of accounts of parents of children with Type 1 diabetes (Lawton et al., 2015; Marshall et al., 2009; Nurmi & Stieber-Roger, 2012; Symons, 2013). Nurmi and Stieber-Roger (2012) described how parents' attempts at providing typical childhood experiences helped the children preserve their identity as regular children by creating a sense that diabetes is a characteristic of the child rather than an illness. In the current study, parents strove to provide their child with typical childhood experiences in the context of significant challenges that diabetes posed to their expected childhoods. Parents invest additional effort in this quest and as suggested by Marshall and colleagues (2009), make this pursuit of normality more apparent.

Contrasting the parents' version of the new normality and preserving of existing normality illuminates the social implications of these ideas. Preserving the existing family normality may be an attempt to not appear different from other families. In this way, this version of normality may take an outward look by comparing their own family to other families. In contrast, when attempts are made to redefine normality to make the diabetes the family's new normal, this takes a more inward look, with the implication that it helps the child with diabetes to not feel different from the rest of the family. Symons (2013) described acceptance of a 'new normal' as an important part of the family adaptation to the illness. Similarly, Lowes and Lyne (1999) described

how changing the whole family's lifestyle to accommodate diabetes can help minimise the child's difference and help them appear more 'normal'. Achieving nondifference appears to be the shared feature in these two key ways of seeking normality for the family. Depending on the situation and circumstances, families could oscillate between these two versions of normality, which demonstrates the usefulness of having multiple versions to suit their situation at a given time. These findings illustrate the wide range of definitions and the more nuanced ways of describing normality for parents and families caring for a child with Type 1 diabetes.

These findings have a number of implications for clinical practice. They indicate the need to understand the impact of the diagnosis of Type 1 diabetes in a child on parents' own biographies and parental identity, and uncover the meaning behind illness for the parents. These results highlight the importance of providing additional support for parents. Examining the repair strategies that parents use to reassert normality can contribute to a more thorough understanding of how parents attempt to cope in their transition to caring for a child with Type 1 diabetes. Health professionals would benefit from understanding this shifting process to supporting parents by providing time to explore their experiences and empathising with their need to adhere to an ideal of normality. For example, understanding that parents' desire to provide the child with a normal childhood is an important aspect in the repair of their identity can help parents in their adjustment. At a service level, health professionals could give parents more opportunities to reflect and voice their experiences, and to reflect the wide-ranging impact of the diagnosis on them.

In the current study, the inclusion criteria involved a duration of six months since the time of diagnosis. This did not allow a more detailed exploration of the impact on parents' biography in the period immediately following the critical transitional moment. Nevertheless, parents were able to relay with vivid details the diagnosis story and how they coped during that time. Future longitudinal qualitative research would allow the tracking of the parental experience over time, to illuminate specific stressors that occur during the illness trajectory to help understand how parental identity shifts. Further research could also explore more specifically the impact of the care-giving role on motherhood and fatherhood. It would also be beneficial to investigate how concepts of normality change over time, and how it is understood in parents of older children with Type 1 diabetes.

Conclusion

An understanding of the parental experience in caring for a child with Type 1 diabetes has been confined by the limited studies exploring the psychosocial impact of the illness in considering parents' lived experiences. Using IPA, the present study highlighted the role of biographical disruption in conceptualising the effect of the illness on the parents' lives. Parents used their familiar experience of having a new baby to relate their experience. The disruption undermined parental confidence in their ability to care for their child, creating uncertainty and ultimately challenging their parental identity. Parents attempted to repair the disruptions to their parental identity by regaining a sense of normality in their lives. A key repair structure involved providing their children with typical childhood experiences, thereby helping them access a more positive parental identity. Understanding the impact of the disruptions on parental identity and the ways that parents seek resolution will help health professionals provide more support for the parents. These findings add to the growing body of research on parental experience in Type 1 diabetes and on biographical disruption in the parental experience of chronic childhood conditions.

References

- Ashbring, P. (2001). Chronic illness- A disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312-319. doi:10.1046/j.1365-2648.2001.01767.x
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet*, 383(9911), 69-82. doi:10.1016/S0140-6736(13)60591-7
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219-234. doi:10.1177/1468794112468475
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, J. A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth. *Diabetes Care*, 31(8), 1516-1520. doi:10.2337/dc07-2349
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182. doi:10.1111/1467-9566.ep11339939
- Bury, M. (1988). Meanings at risk: The experience of arthritis. In R. Anderson & M. Bury (Eds.), *Living with chronic illness: The experience of patients and their families* (pp. 89-116). London: Unwin Hyman.
- Bury, M. (1997). *Health and illness in a changing society*. London: Routledge.
- Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: The case of HIV-positive men. *Sociology of Health & Illness*, 17(1), 65-88.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168-195. doi:10.1111/1467-9566.ep10491512
- de Boer, I. H., Rue, T. C., Cleary, P. A., Lachin, J. M., Molitch, M. E., Steffes, M. W., . . . Brunzell, J. D. (2011). Long-term renal outcomes of patients with Type 1 diabetes mellitus and microalbuminuria: An analysis of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications cohort. *Archives of Internal Medicine*, 171(5), 412-420. doi:10.1001/archinternmed.2011.16
- Dickson, A., Allan, D., & O'carroll, R. (2008). Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis. *Psychology & Health*, 23(4), 407-425. doi:10.1080/14768320701219136

- Doyle, E. A., & Grey, M. (2010). Diabetes mellitus (types 1 and 2). In P. J. Allen, J. A. Vessey & N. A. Schapiro (Eds.), *Primary care of the child with a chronic condition* (5th ed.). St. Louis, Missouri: Mosby Elsevier.
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). Los Angeles: Sage Publications.
- Harden, J. (2005). Parenting a young person with mental health problems: Temporal disruption and reconstruction. *Sociology of Health & Illness*, 27(3), 351-371. doi:10.1111/j.1467-9566.2005.00446.x
- Hilliard, M. E., Monaghan, M., Cogen, F. R., & Streisand, R. (2011). Parent stress and child behaviour among young children with type 1 diabetes. *Child: Care, Health and Development*, 37(2), 224-232. doi:10.1111/j.1365-2214.2010.01162.x
- Jönsson, L., Lundqvist, P., Tiberg, I., & Hallström, I. (2015). Type 1 diabetes: Impact on children and parents at diagnosis and 1 year subsequent to the child's diagnosis. *Scandinavian Journal of Caring Sciences*, 29(1), 126-135. doi:10.1111/scs.12140
- Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, 55(3), 320-329. doi:10.1111/j.1365-2648.2006.03899.x
- Lawton, J., Waugh, N., Barnard, K. D., Noyes, K., Harden, J., Stephen, J., . . . Rankin, D. (2015). Challenges of optimising glycaemic control in children with Type 1 diabetes: A qualitative study of parents' experiences and views. *Diabetic Medicine*, 32, 1063-1070. doi:10.1111/dme.12660
- Lowes, L., & Lyne, P. (1999). A normal lifestyle: Parental stress and coping in childhood diabetes. *British Journal of Nursing*, 8(3), 133-139. Doi:10.12968/bjon.1999.8.3.6698
- Lowes, L., Lyne, P., & Gregory, J. W. (2004). Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*, 21(6), 531-538. doi:10.1111/j.1464-5491.2004.01193.x
- Marshall, M., Carter, B., Rose, K., & Brotherton, A. (2009). Living with Type 1 diabetes: Perceptions of children and their parents. *Journal of Clinical Nursing*, 18(12), 1703-1710. doi:10.1111/j.1365-2702.2008.02737.x
- Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. C. (2014). Family cohesion and health-related quality of life of children with Type 1 diabetes: The mediating role of parental adjustment. *Journal of Child and Family Studies*, 23, 347-359. doi:10.1007/s10826-013-9758-6

- Nurmi, M. A., & Stieber-Roger, K. (2012). Parenting children living with Type 1 diabetes: A qualitative study. *The Diabetes Educator*, 38(4), 530-536. doi:10.1177/0145721712446636
- Owens, C., Lambert, H., Lloyd, K., & Donovan, J. (2008). Tales of biographical disintegration: How parents make sense of their sons' suicides. *Sociology of Health & Illness*, 30(2), 237-254. doi:10.1111/j.1467-9566.2007.01034.x
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, California: Sage Publications.
- Pop-Busui, R., Low, P. A., Waberski, B. H., Martin, C. L., Albers, J. W., Feldman, E. L., . . . Herman, W. H. (2009). Effects of prior intensive insulin therapy on cardiac autonomic nervous system function in Type 1 diabetes mellitus: The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study (DCCT/EDIC). *Circulation*, 119(22), 2886-2893. doi:10.1161/CIRCULATIONAHA.108.837369
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of parenting children with Type 1 diabetes diagnosed early in childhood. *Journal of Pediatric Health Care*, 25(2), 87-95. doi:10.1016/j.pedhc.2009.09.003
- Smith, J. A., & Eatough, V. (2006). Interpretative phenomenological analysis. In G. M. Breakwell, S. Hammond, C. Fife-Schaw & J. A. Smith (Eds.), *Research methods in psychology* (3rd ed., pp. 322-341). London: Sage.
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in Psychology* (pp. 35-50). Los Angeles: Sage.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London: Sage.
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing*, 18(1), 21-29. doi:10.1053/jpnd.2003.4
- Symons, J. M. (2013). *The impact on the family of living with a child with Type 1 diabetes*. (Unpublished master's thesis). Eastern Institute of Technology, Taradale, New Zealand.
- Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, 7(2), 213-225. doi:10.1348/135910702169457

- Todd, S., & Jones, S. (2005). Looking at the future and seeing the past: The challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(6), 389-404. doi:10.1111/j.1365-2788.2005.00675.x
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with Type 1 diabetes. *The Diabetes Educator, 38*, 562-579. doi:10.1177/0145721712445216
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness, 22*(1), 40-67. doi:10.1111/1467-9566.00191
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Philadelphia: Open University Press.
- Wilson, S. (2007). 'When you have children, you're obliged to live': Motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness, 29*(4), 610-626. doi:10.1111/j.1467-9566.2007.01008.x
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215-228. doi:10.1080/08870440008400302
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science & Medicine, 55*(10), 1835-1847. doi:10.1016/S0277-9536(01)00318-5



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STATEMENT OF CONTRIBUTION
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(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Fathimath Rifshana

Name/Title of Principal Supervisor: Dr. Mary Breheny

Name of Published Research Output and full reference:

Biographical Disruption and the Pursuit of Normality in the Parental Experience of Caring for a Child with Type 1 Diabetes

In which Chapter is the Published Work: Chapter 4

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The candidate is responsible for the analysis and write-up of the manuscript. The supervisors contributed to the manuscript by providing guidance on structuring arguments and the clarity of the write-up.

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CHAPTER 5: MAKING SENSE OF HARDSHIP: EXPLORING RESILIENCE IN THE PARENTAL EXPERIENCE OF CARING FOR A CHILD WITH TYPE 1 DIABETES

Rifshana, F., Breheny, M., Ross, K., & Taylor, J. (2017). *Making sense of hardship: Exploring resilience in the parental experience of caring for a child with Type 1 diabetes*. Manuscript in preparation.

Abstract

The aim of the study was to explore parental coping by studying the experiences of resilience among parents with a child diagnosed with Type 1 diabetes. Seventeen parents were interviewed about the experiences of caring for their child and the interviews analysed using Interpretative Phenomenological Analysis. Parents' accounts of resilience reflected a mainstream understanding of resilience as an individual attribute or capability. However, the parents' talk of navigating daily challenges revealed an alternative conceptualisation of resilience as 'doing' resilience. 'Doing' resilience involved a separation of actions and emotions of the parents, which supported parents in the daily 'doing' of diabetes. The processes of acceptance and resignation, spirituality and crafting resilience from supportive environments are discussed in terms of how they help parents enact resilience. Resilience conceptualised in this way provides a more meaningful perspective for parents experiencing the daily challenges of caring for their child with Type 1 diabetes.

Introduction

Caring for a child with Type 1 diabetes poses significant challenges for parents who carry out or oversee much of the treatment. Type 1 diabetes, which is one of the most common chronic conditions of childhood, involves a complicated treatment regimen entailing insulin therapy, management of diet and activity levels, and frequent blood glucose monitoring to maintain blood glucose levels within a certain range (Doyle & Grey, 2010). The maintenance of normal blood glucose levels with intensive therapy has been shown to delay the onset and slow down the progression of diabetes-related complications, such as nerve damage, blindness and amputations (de Boer et al., 2011; Pop-Busui et al., 2009). Hence, parents invest great efforts towards good diabetes control to provide their child with a future with fewer complications.

This demanding caregiving role has been associated with several psychosocial consequences for the parents. Parents have reported experiences of grief and loss, depression, anxiety and stress, and constant vigilance (Buckloh et al., 2008; Lowes, Lyne, & Gregory, 2004; Sullivan-Bolyai, Deatrck, Gruppuso, Tamborlane, & Grey, 2003; Whittemore, Jaser, Chao, Jang, & Grey, 2012). While research to date has demonstrated the impact of the diagnosis on the parents, much less attention has been paid to the ways that parents cope. Parental coping with stress resulting from diabetes can have important implications for both the child's and parental psychosocial adjustment. Quantitative research has attempted to study parental coping by looking at the relationship between coping and outcomes for parents and the child, such as levels of depression, quality of life, and metabolic control (Driscoll et al., 2010; Jaser, Whittemore, Ambrosino, Lindermann, & Grey, 2008; Jaser, Whittemore, Ambrosino, Lindermann, & Grey, 2009; Streisand, Mackey, & Herge, 2010; Whittemore, Urban, Tamborlane, & Grey, 2003). Using pre-determined measures of coping reflects researchers' views rather than parents' views of coping and thus provides a limited understanding of parental perspectives. As Ungar (2008) described, many survival processes are idiosyncratic. Much variation exists in coping processes, within and between individuals, across time and context. Hence, an approach that allows parents to describe their unique ways of coping is needed, to demonstrate the myriad of ways that they cope with their child's diabetes.

Exploratory qualitative research allows parents' voices to be heard, and takes into account their subjective and context-driven experiences of coping with their child's diabetes. Qualitative research has described phases of coping (Seppänen, Kyngäs, & Nikkonen, 1999), effective coping strategies used by parents of children with diabetes such as patience, persistence, flexibility, creativity, maintaining a positive attitude,

humor, hope, spirituality and social support (Whittemore et al., 2012), and conditions that helped with parental coping such as the child's cooperation with diabetes and the cost of treatment (Oskouie, Mehrdad, & Ebrahimi, 2013). These strategies demonstrate the variety of internal and external resources that parents are able to tap into or improve as they transition to the demanding caregiving role. However, there is a paucity of in-depth qualitative research that explores the lived experiences of coping from the perspective of parents themselves. The current study aimed to explore parental coping by using the qualitative methodology of Interpretative Phenomenological Analysis (IPA) to allow parents to voice what it means to care for a child with Type 1 diabetes and to explore what coping was for them. The concept of resilience formed the conceptual basis to explore coping in this study.

Resilience

Resilience is a complex concept, with several definitions existing in the literature. Resilience generally refers to positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). Within this literature, two conditions are considered central to this concept: the presence of a significant adversity and the achievement of a positive outcome (Masten, 2001). The focus on resilience comes from a salutogenic orientation, which emphasises healthy functioning over pathology (Antonovsky, 1987). Early seminal research on resilience was focused on identifying characteristics of individuals who appeared to function well despite adversity (Garmezy, 1991; Rutter, 1987; Werner & Smith, 1992). However, this conceptualisation portrays resilience as an intra-psychoic construct or an atypical static inner trait (Ungar et al., 2007).

There are several criticisms of this mainstream static and internal understanding of resilience. The expectation that special qualities are needed to overcome adversity implies ordinary adaptive processes are insufficient (Masten, 2001). In addition, this intra-psychoic approach potentially ignores the possibility that resilience could be a social phenomenon (Lenette, Brough, & Cox, 2012). The social dimension of resilience as occurring within the person-environment demonstrates resilience as an ongoing process achieved over time and according to contexts rather than as an atypical inner trait (Lenette et al., 2012). In addition, the idea that resilience emerges from ordinary processes provides a more optimistic outlook than the idea that resilience involves extraordinary and rare processes (Masten, 2001).

Resilience research then broadened to explore ecological factors that may explain individuals' resilience (Aranda et al., 2012). An ecological perspective advances the idea of resilience as a result of individuals' embeddedness in complex and dynamic

social contexts (Harvey, 2007). As a result, resilience definitions began to describe it as a process. Richardson (2002, p.308) defined resilience as “the process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors”. However, this process conceptualisation of resilience paved way to mainly quantitative research attempting to identify causal relationships between risk and protective factors and transactional processes thought to enhance resilience (Hatala, Waldram, & Crossley, 2013). For examples, studies examining parental resilience within childhood disability and chronic conditions have used pre-determined indicators of resilience and attempted to identify individual attributes that determined health outcomes (Bitsika, Sharpley, & Bell, 2013; Gerstein, Crnic, Blacher, & Baker, 2009; Gudmundsdottir, Schirren, & Boman, 2011). In this conceptualisation, resilience is still ‘found’ mainly within individuals as an a priori psychological state, even if it originates from repeated interactions between a person and their environment (Aranda et al., 2012). This mainstream perspective also contributes to the false dichotomy of resilient and non-resilient, where resilience is judged on arbitrary assumptions about what is considered a positive or negative outcome (Ungar, 2003). Although the concept of resilience was originally applauded for its salutogenic approach, this dichotomy perpetuates a pathological discourse and undermines the efforts of individuals living through adversity.

An alternative account of resilience posits that resilience is something that is ‘made’, as opposed to the internal understanding of resilience (Aranda et al., 2012). Ungar (2008) proposed the following definition of resilience from this approach:

“In the context of exposure to significant adversity, whether psychological, environmental, or both, resilience is both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of wellbeing, and a condition of the individual’s family, community and culture to provide these health resources and experiences in culturally meaningful ways” (Ungar, 2008, p.225).

This definition emphasises how resilience is culturally and socially produced (Aranda et al., 2012). This view of resilience explicitly embraces diversity in the way resilience is nurtured and maintained (Ungar, 2004). Bottrell (2009) asserts that cultural practices, social processes, social change and the nature of individual-social interactions are significant aspects in analysing the concept of resilience. Research supported by this view has emphasised a non-systemic, non-hierarchical relationship between risk and protective factors, and highlights the chaotic, complex, relative, and contextual

relationships within these factors among cultures and diverse social and political settings (Ungar, 2004).

There is a lack of research exploring the experiences and understandings of resilience in the context of caring for a child with Type 1 diabetes. The only previous study that focused on parental resilience in childhood diabetes investigated the relationship between hope and parental distress, where hope was conceptualised as a resilience factor (Mednick et al., 2007). Such research based on the ecological model fails to accommodate the multitude of meanings that individuals attribute to resilience (Ungar, 2004). A qualitative approach to studying resilience can reveal the wide array of individuals' perceptions on the concept and their lived experiences of the phenomenon. This approach can facilitate thick descriptions of the phenomenon in very specific contexts, providing the opportunity to discover unnamed processes and reveal novel aspects of resilience and thriving (Massey, Cameron, Ouellette, & Fine, 1998; Ungar, 2003). It provides an opportunity to develop understandings of resilience that go beyond restrictive traditional definitions, while taking into account the social and cultural context in which resilience occurs (Anderson, 2010; Ungar & Liebenberg, 2005). The current study used Interpretative Phenomenological Analysis (IPA) as the method of analysis to explore parental experiences of resilience in the context of caring for a child with Type 1 diabetes. The definition provided by Ungar (2008) was used to examine the concept of resilience within this context.

Method

Participants

Participants in this study were parents of children aged between four and twelve years who had been diagnosed with Type 1 diabetes for a minimum of six months. Participants were recruited from three main district health services that provide specialist care for people with diabetes in New Zealand. These services mailed out an information sheet for the study to the families in their database meeting the study criteria. Parents interested in taking part in the study contacted the researcher. A total of 17 parents (14 mothers and three fathers) were interviewed before data saturation had occurred. While the information sheet invited both parents to participate, in the majority of families, mothers volunteered to take part. Both parents were interviewed at the same time in two interviews. One participant had two children diagnosed with Type 1 diabetes, with the younger child's age within the inclusion range. Table 1 summarises the participant characteristics.

Table 1

Demographic Characteristics of Participants and their Children

| | N | Mean | Range |
|-------------------------------|----|------|----------|
| Parents | 17 | | |
| Parental age (years) | | 40 | 28-54 |
| Relationship to child | | | |
| Mother | 14 | | |
| Father | 3 | | |
| Ethnicity | | | |
| New Zealand European | 15 | | |
| New Zealand Māori | 1 | | |
| Other European | 1 | | |
| Relationship status | | | |
| Married/cohabiting | 13 | | |
| Separated/divorced | 4 | | |
| Employment | | | |
| In paid employment | 9 | | |
| Not in paid employment | 8 | | |
| Children | 15 | | |
| Child's age (years) | | 9 | 5-12 |
| Child's gender | | | |
| Female | 8 | | |
| Male | 7 | | |
| Age at diagnosis (years) | | 4.50 | 1.16- 10 |
| Duration of diagnosis (years) | | 4 | 0.75-9.5 |

Procedure

The present study involved in-depth semi-structured interviews, conducted by the first author. With the exception of one interview, all other interviews were conducted at the parents' own homes. An interview schedule with open-ended questions was used as a general guide to facilitate the discussion. The interview schedule was compiled with the overarching aim of exploring parental experiences of caring for a child with Type 1 diabetes. The interview began with more general questions such as "Tell me about when you first found out that your child had diabetes". These were then followed with more specific questions such as "What was the hardest part about it?" and "What worries you the most about your child having diabetes?" to allow parents to voice the challenging aspects of their caregiving. Questions meant to elicit talk about coping and adjusting were then asked, such as "How do you think you have come to terms with your child having diabetes?", "How do you think you have adjusted and coped with the experience?" and "What have you found helpful for coping?". Further questions such as "Are there any good things that came out from this experience?" and "What are some of your family strengths?" were asked to give parents opportunity to highlight any positive experiences. Follow-up questions and prompts were used to further explore parents' concerns and experiences. The

participants were encouraged to highlight issues salient to them at any point during the interview. The interviews lasted between 45 minutes to two hours. Interviews were digitally recorded and transcribed verbatim by a professional transcriber. The transcripts were reviewed for accuracy by the first author. A copy of the transcript was made available to those who requested it. Data collection occurred between May 2012 and November 2012. Ethical approval was granted by the Central Regional Ethics Committee of the Health and Disability Ethics Committees.

Data Analysis

IPA was chosen as the method of analysis for this research to enable an in-depth examination of the unique lived experiences of adjustment and coping described by parents who have a child diagnosed with Type 1 diabetes. IPA commits to examining individuals' lived experiences in detail and understanding how individuals make sense of those experiences (Eatough & Smith, 2008). The term 'lived experience' has been used by researchers to represent the embodied, socio-culturally and historically situated person present in an intentionally interpreted and meaningfully lived world (Eatough & Smith, 2008). IPA addresses different aspects of this lived experience, ranging from individual's wishes, desires, feelings, motivations, and belief systems through to how these are translated into behaviour and action (Eatough & Smith, 2008). IPA is also useful for exploring process. Rich information about the *process* of adjustment can be provided by IPA (Thompson, Kent, & Smith, 2002), in contrast to methods that emphasise adjustment *outcomes*. In the current study, the exploration of processes of coping and adjustment rather than factors or adjustment outcomes was more salient.

Data analysis was commenced after the completion of all interviews. The interview transcripts were analysed using IPA by following a series of steps as described by Smith and Osborn (2008). The first step involved reading through each transcript and noting initial thoughts and possible codes on the margin. Then, the transcripts were re-read to code initial themes, where the coding was kept at a broader level. Next, the themes were organised into meaningful clusters and higher-order themes were developed. A descriptive label was given to each cluster to express the conceptual nature of the themes involved (Smith & Eatough, 2007). At the end of the process, a summary of the higher-order themes was developed.

The next stage involved closely examining the most salient higher-order themes. Once a theme was selected for further analysis, the transcripts were examined again to select the extracts coded under the theme, copying them into a new word-processed file. For this paper, extracts that were coded under coping, acceptance and aspects of

resilience were selected for further analysis. Each individual extract was then analysed and coded. Themes were then formed from closely related codes. The final stage involved transforming this structure of themes into the write-up of results.

The rigor and trustworthiness of the current study was ensured by considering the guidelines for evaluating qualitative research suggested by Yardley (2000). The transcripts were read multiple times alongside the developing themes, to ensure that the themes were grounded in the data. While all transcripts were analysed in detail by the first author, all authors were involved in the development, mapping and refining of themes to ensure the reliability of the final account. The transparency of the study was supported by describing the research sample, settings and procedures in detail. Reflexivity ensured a consideration of the researcher's characteristics on the research process and outcome (Berger, 2015). In the reporting of the results of the study, the selected extracts were edited to ensure confidentiality. All personal and identifying information were removed and pseudonyms placed where people's names appear. The interviewer's questions and comments appear within brackets { }. Observations during the interview, such as pauses and participant reactions, such as laughter are indicated inside square brackets [].

Results

All parents described ways in which they coped with caring for a child with Type 1 diabetes. The concept of resilience guided the analysis as the framework to understand parental coping through adversity. Parents mostly drew on the mainstream psychological understanding of resilience as something residing in them. Resilience was understood as an experience of capability within themselves that allowed them to cope with the challenges of diabetes. However, parental accounts indicated that they were 'doing' resilience, a notion located within their explanations of everyday coping, and grounded in navigational efforts to promote their own wellbeing. 'Doing' resilience also involved a critical separation between actions and emotions, which highlighted how resilience was more about actions rather than emotions. Processes that fostered 'doing' resilience are also described below.

Parental Accounts of Resilience

Resilience was described as a characteristic residing within parents or the family that related to their ability to cope with the challenges of parenting their child with diabetes: "...no drama is going to be too big a drama for, for either of us, you know we're just resilient, I would say we'll just cope". The diabetes experience itself was described as building resilience: "I think it's made us a bit tougher, bit more resilient to

um certain things. We know we've handled, we're handling a toughie and we, we've done it okay so you know we can handle pretty much anything". Resilience was described as a generalised experience of confidence and capability within themselves and a sense of having internal resources that will help them cope with challenges. It was understood as a trait that has been enhanced and which can be applied to future difficult situations.

These internal resources were understood as developed through life experiences. One parent described the learnt aspect of resilience:

I don't know where I got my natural resilience from, I think my father probably has a strong, he's a very optimistic, you can do anything sort of, which is how I was raised to believe ... And we were taught, we believed that right from birth. So now I'm just like, that's what I believe and that's what, and um, and resil, we've always been taught that we could handle anything. We could do anything. And there was nothing that was ever big enough to take either of us out or down. (Participant 5, Mother: Daughter, 9 years).

Here, resilience is understood as a trait embedded in individuals as a genetic endowment or learned through childhood experiences and able to be enhanced. This understanding of resilience as a learning process also enables the mother to incorporate it into her own parenting practices and teach it to her children, where she passes down messages to them; "I've always taught the kids that we can handle anything, it's fine". This mother further describes the impact of this strategy, in terms of how her daughter had coped with the diagnosis "...was really nice when she was diagnosed, she'd say things to me like, we'll be fine eh, we can do this, cause we can do anything. And I was like oh yay, it's working you know so luckily she had a bit of resilience before we started, so I think that's probably helped". This understanding of resilience as located within an individual and able to be taught allows parents to view themselves as being capable of enduring hardships and able to instill such characteristics in their children.

Resilience was also regarded as something that can be learnt from earlier adult life experiences. One parent recalled her past experience of successful coping with another life challenge:

And my friend said look, you felt like this about celiac disease and now it's not even an issue. It's so fine. She said you'll be like this with diabetes in five years and I went oh [sighs] yeah that's true. That's fine. So then I thought no that's fine, yeah we can do this. (Participant 5, Mother: Daughter, 5 years).

Understanding resilience in this way means that parents are able to draw confidence and reassurance from past experiences of struggling and coping and apply it to the new challenge of diabetes. This understanding of resilience as growing through difficult experiences means that parents develop an expectation that with time, coping with diabetes will get easier: “it’s just a journey that you...seem to be on a roller coaster ride and somewhere along the line, resilience pops in, you know you learn to roll with what’s happening”. Resilience was viewed as dormant until realised with the diabetes experience.

‘Doing’ Resilience

Parents did not always use the word ‘resilience’, and not all parents described themselves as ‘resilient’ per se when describing their lived experiences of caring for their child with Type 1 diabetes. However, in the interviews, there were striking accounts of how these parents were ‘doing’ resilience versus simply ‘being’ resilient. These were implicit within their ways of coping with the everyday challenges of caring for their child and family in general. On a daily basis, parents are responsible for ensuring their child’s blood sugar levels are maintained within a healthy range. They constantly monitor the child’s food intake and activity levels. Parents spoke about regularly communicating with school and other carers about the child’s needs. Parents also talked about the challenges in attending to their other children’s needs, when much of their time was absorbed by diabetes management. These parenting demands had to be fulfilled day in and day out, with no exception. Parents’ unique ways of coping within the context of these challenging demands represented efforts to manage their wellbeing and fits with Ungar’s (2008) definition of resilience; “resilience is both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of wellbeing, and a condition of the individual’s family, community and culture to provide these health resources and experiences in culturally meaningful ways (2008, p.225)”. Understood in these terms, resilience is better thought of “as a verb, the actions that individuals perform to negotiate and navigate health and wellbeing within their local social and moral worlds” (Hatala, Waldram, & Crossly, 2013, p. 153). Adaptive efforts that worked to enhance their wellbeing suggest how parents were engaged in ‘doing’ resilience. The dynamic nature of resilience can be seen in this process where resilience is located in the different ways that parents persist with their everyday actions, as opposed to being seen as a property or a characteristic of an individual.

Coping was seen as action-oriented and movement based, evident from descriptions such as “just keep on, keeping on, and don’t look back”, “you need to just keep on get,

keep on getting on you know and, and one day at a time and, and just keep, keep going”, and as one parent mentioned “I really like that poster- keep calm and carry on- and sometimes that’s all you can do”. Several understandings existed about what helped them carry on. One mother attributed it to a key identity such as motherhood (“luckily once you become a mum you kind of get up and keep going”), whereas some parents described particular strategies that denoted ‘doing’ resilience. The following extract shows an example where the strategy involved envisioning each day as a “fresh start”:

..some days I just have to give up and think we’ll start again tomorrow. And sometimes that’s the only way I get through the day is yeah, tomorrow we’ll start off again and ...{Int: Fresh start}. Fresh start, yeah. I haven’t managed to kill them yet so I figure that [laugh] you know it’s a case of um try again tomorrow and maybe we’ll be better managed tomorrow. (Participant 10, Mother: Son, 8 years).

By treating each day as a fresh start, this mother is able to let go of the frustrations of the current day and continue with her commitment to good diabetes management in her child. She is able to take the next day as another opportunity to have things go more to plan. Letting go of diabetes management today can leave her in a better position to cope better tomorrow. The mother’s giving up in the short term can be viewed as part of ‘doing’ resilience, as giving up completely was not an option. In this way, this mother is seen to navigate the challenging situation of diabetes management by engaging in a coping strategy that ultimately allows her to ease the burden and manage her own wellbeing. The broader socio-environmental context of this parent shapes this practice. As a single mother and a full-time carer for more than one child, this mother has limited opportunities for respite and managing her own wellbeing. Having this personal coping strategy to “get through the day” during times of difficult diabetes management and limited external support and financial resources may form an important part of her self-care.

Parental descriptions of coping suggest that an integral part of ‘doing’ resilience involves a separation of actions and emotions and finding ways to manage emotions:

Yeah we always have our struggling days. Yeah. But that’s when you just shove it at the back of your head and think today’s another day, you know. And you got to, cause otherwise, it’s like anything, I mean I was told of a forty year old that had diabetes, he was diagnosed and he just didn’t want to do anything. Just sat at home and didn’t do anything. And he denied it and didn’t take his injections

and he got really sick. And he was 40 and I think well you know, so I think nah you just got to, yeah just have to get on with it. (Participant 15, Mother: Daughter, 7 years).

This mother's strategy of "shove it at the back of the head" allows her to separate her daily frustrations from her commitment to good diabetes management, helping her to be more focused on the daily actions required of diabetes. Her example of an adult who "denied" his condition demonstrates someone who refused to 'do' diabetes management. By stating that "you just got to", she separates her emotions from her actions, the 'doing' of diabetes, suggesting that resilience is more about the actions rather than emotions. During the interview, she used the phrases "shove it", "push it" or "chuck it at the back of the head" multiple times, along with a hand gesture that signalled her pushing something behind her head. From a mainstream psychological perspective, this could be viewed as avoidance or compartmentalisation of emotions, which this parent also acknowledges when she said "...and my strength is, is chuck it over the shoulder, you know and I do that heaps, and I shouldn't cause you know they say it's bad to do that". However, this was a deliberate choice which allowed her to do what needs to be done to carry on, by focusing on the 'doingness' of everyday actions. She commented that she would regularly "let it all out" with a close friend as a way of dealing with her emotions. In this way, emotions are 'parked up' and stored until they can be dealt with safely.

For this mother, diabetes management needed to fit into a busy family life. Even though she did not work outside the home, having extra demands with caring for other children can mean reaching a balance between diabetic needs and family needs; "I just try and put it to the back of my head, I've got other kids to worry about as well and I just can't concentrate just on her". This social context shapes her practice of separating actions and emotions, which can promote her sense of wellbeing. This finding highlights the place of emotions in the parents' experiences of resilience, and how it is managed by parents on their own terms. Recognising the place of emotions in their daily coping can be seen to promote parents' sense of wellbeing and is consistent with Ungar's (2008) definition of resilience.

Processes that Help Parents 'Do' Resilience

Parents described several processes that fostered their performance of resilience within their everyday actions. Some of these processes operated at an individual psychological level to support the separation of emotions in order to 'do' diabetes, whereas some worked to enhance 'doing' resilience through the wider social context. These indicate the plurality of pathways to 'doing' resilience.

Acceptance and Resignation

Parents talked about the different ways they came to terms with their child being diagnosed with Type 1 diabetes when describing their coping. There were notions of acceptance and resignation within the parents' talk of their situation. They were used as ways to manage the difficult emotions that arise to enable parents to focus on the daily work required of diabetes. However, the experience of acceptance was different between parents, and there appeared to be more complex layers of acceptance, indicating the tensions apparent in the process. Acceptance can be defined as the recognition of the realities associated with having a chronic condition (Zalewska, Miniszewska, Chodkiewicz, & Narbutt, 2007). A sense of a resigned acceptance was evident in some parental accounts:

He's got to change his ways and he does have to prioritise things and manage it, which he'll do for the rest of his life but it's just what it is now. And I think that's what we had from the beginning, wasn't it? (Father: Mm). We can't change it. It is what it is and you've, we've just got to do the best that we can. (Father: Yeah there's no point, well obviously you do worry but there's no point ...). (Participant 13, 14, Mother and Father: Son, 9 years).

These parents have been living with the challenge of diabetes in their child for the past two years. At this point, there are no other choices but to resign themselves to the fact that their child has this chronic illness. The phrase "it is what it is", carrying a notion of finality, could indicate an acceptance of the limitations that come with the disease and of their current reality. This process could be seen to motivate 'doing' resilience by providing a way for parents to organise their emotional experience of diagnosis and the transition to caring for their child. It helps parents move forward into the future from these experiences and "do the best we can". It can be seen as an important action-oriented and adaptive process that promotes their wellbeing. The father further emphasises the unproductive nature of an emotion such as worry by the phrase "you do worry but there's no point".

While acceptance appeared as a key way that parents came to terms with their child having Type 1 diabetes, this was not a straightforward process, indicating the tensions that parents experience. Some parents described their unwilling acceptance, or non-acceptance, that arose from their hope for a cure:

I've accepted that she's got it, I know that she's got it, and I'm dealing with the fact that she's got it but you never really go, right, this is it, forever, you know, this you can't look at it going this is gonna go on day in day out till she dies, you

know she's gonna have to go through everything as well as this, um cos you always still kinda do hope for that cure. (Participant 4, Mother: Daughter, 11 years).

For this mother, her acceptance of the condition may have been helped by the eight years that had passed since the diagnosis. However, her non-acceptance can be seen to serve the function of keeping alive her hope for a cure. In this way, non-acceptance of the chronicity of the illness experience can be viewed as not giving up. This provides an opportunity for parents to balance acceptance with hope. Similar to acceptance, hope is also a forward looking strategy, one that promises a better future. Parents have a need to hold onto this hope to be able to move forward with the future which is possible today. Hope can support parents in 'doing' resilience by allowing them to anticipate a better future while they carry on with the unrelenting daily 'doing' of diabetes.

Another tension in the acceptance process was the recognition that even after acceptance, there were still ongoing challenges that parents had to contend with. Acceptance alone did not alter the daily experiences of living with the illness for this mother, whose daughter had been diagnosed only one year earlier:

And she's got it so, so I didn't really find, accepting it wasn't that hard I don't think. Didn't even think about it really, just did it. It was the doing that was harder than the accepting [laugh], cause it was so physically challenging I think, from every angle like from tired, tired, money, time, stress. All of the boxes eh really, yeah. (Participant 5, Mother: Daughter 9 years).

The above extract indicates that there are on-going challenges that are still left after acceptance such as the physical and financial struggles involved with the disease. These accounts indicate the limits of the processes of acceptance and resignation, where at times it does not alleviate their everyday work of caring for their child with diabetes.

Strength from Spirituality

Parents often talked about relying on religion or faith as a way of coping with their challenges in parenting a child with Type 1 diabetes. For some parents, this spiritual basis was not related to any particular religion. Spirituality could be seen as creating a space for the parents in 'doing' resilience, as the sense-making process involved frees them up to do the daily work of diabetes. It could provide a way of answering the 'why us?' of diabetes and help them manage the painful emotions that arise from the

diagnosis. This enables parents to locate their experience within a larger purpose, helping them persevere with their everyday challenges. Several parents remarked how “everything has its reasons”, “God doesn’t do anything by accident” and “we’re meant to do this and this was all part of the plan for us”, implying a sense that this is what has been chosen for them. A connection to something bigger than themselves helps them to re-direct their focus away from diabetes and view their difficulties from a broader and more distant perspective.

Faith also supported the separation of emotions and ‘doing’ of diabetes by being an important source of emotional support. It provides an avenue to cast the most distressing aspect about diabetes, the lack of a cure, to a higher power, easing the emotional burden. It was described as a medium of expressing wishes, such as a wish for a cure of the child through the act of praying. Another way that spirituality helped to relieve the emotional burden was how it may help with the feeling of isolation:

So um, and with, with everything happens, you know, I trust in the Lord and yeah, we’ll get through it... It’s not just me doing it on my own. Yeah, there’s somebody else there that’s looking after our family and, yeah, that’s really important to me.
(Participant 10, Mother: Son, 8 years).

For this single mother, imagining the Lord to be alongside her in her struggles, served as an important emotional support. For these parents, placing their trust in a higher power provided a way to manage difficulties that were too challenging to cope with by themselves. Having to continuously face the challenge was also interpreted by this parent as strengthening her faith rather than undermining it: “It’s growing stronger...growing stronger with each...new challenge...yeah it’s increased the trust”. This is particularly relevant with Type 1 diabetes, as parents experience shifting demands and challenges with the illness experience. This increase in faith appears similar to how parents described resilience growing stronger with hardship.

Crafting Resilience from Supportive Contexts

Resilience can also be viewed as transactional and as residing within the social context of the parents. This social dimension of resilience was demonstrated by parents’ descriptions of how they attempted to create more supportive environments and enact response systems that encouraged parents in ‘doing’ resilience. Parents sought the support of partners, family, friends, health professionals and the community. These were seen as important health-enhancing social environments that helped parents in their daily work of diabetes. In this way, the social context powerfully shaped ‘doing’ resilience, by contributing to culturally relevant ways that promoted

parental wellbeing. This view of resilience as fostered by person-environment interactions demonstrates how resilience is not located in individuals.

Parents described opening up to others as an essential approach that would allow them to help parents to carry on with their daily work of diabetes. One parent described the idea behind this being “a problem shared is a problem halved”:

I'm a great believer that the more people know about what's going on, especially with the likes of Amy with all of her issues, the more likely you are to get understanding from people and information from people that might actually lead you in a direction of helping you, to understand it better or give you ideas of how to cope. (Participant 2, Mother: Daughter, 12 years).

The mother emphasises how parental coping is enhanced by sharing your difficulties with others. In her case, the difficulties described may have been magnified with having to manage more than one chronic condition in her child. In this way, ‘doing’ resilience is fostered by the parents’ interaction with their environment by how it supports parental coping and wellbeing. Another parent’s strategy involved ignoring unhelpful remarks from people and selectively listening to the encouraging messages from supportive people. Having someone else affirming in your ability to cope was seen as helpful; “you needed people to go ‘you’ll be fine’”.

Many parents talked about the invaluable support they received from family. A few parents described how they moved to be closer to their family for more emotional and instrumental support. Family was understood as integral to parental coping as they can share the same long-term goals for the child with diabetes. Families were seen as supporting ‘doing’ resilience by helping parents manage difficult emotions from time to time, and also with the everyday ‘doing’ of diabetes.

One parent described the accessibility of support provided by her family, which supported her coping:

...they're just a text or a phone call away or just a little short drive down the road um, they know what to say, when to say... they're just there, whenever you need them, accessible, you know shoulder to cry on if you need it, hug when you need it. They just, they keep you in check. They support you positively through it. (Participant 4, Mother: Daughter, 11 years).

This mother described how her coping was enhanced by the willing involvement of her family, who were emotionally sensitive and responsive and would oversee diabetes

management at times when she was unable to. This allowed her to take the necessary breaks from parenting and engage in activities that promoted her own wellbeing. Another parent described an example where a grandparent was able to help her with the repetitive blood glucose checking; “Mum started up a system really early on with Amy... she had a lucky dip bag, and mum used to go to the two dollar shop and buy packets of erasers, pencils...plastic animals packets and she would individually wrap them all up...so whenever she went to nanna and granddads and she needed an injection from them, she was allowed a lucky dip”. By coming up with an innovative strategy for the tedious task of regular blood-glucose checking, this grandparent was able to support the parents in an active and practical way.

Another source of support frequently described was that of partners. One parent highlighted the crucial support between partners and the value of teamwork: “But I think yeah I don’t know how you cope if you didn’t have someone to sort of throw the ball to every now and then. And some nights [husband’s] like I’m done, I’m so over this today or I’m like I can’t handle her so you deal with her and we, it’s really, really good that we have that ability to do that I think”. Shared breaks and respite can be an invaluable resource in helping parents manage their own physical and psychological health as they carry on with their daily work of caring for their child.

Parents also spoke about the support they received from the school or daycare centre their child attended. This forms an important social context for the child and the parent, as parents rely on their cooperation in managing the child’s diabetes during the significant amount of time they spend in this environment. Their support can ultimately contribute to parental coping as it can provide parents the reassurance they need that their child will be safe while in their care. One parent described how she sought a teacher’s help with managing blood sugar levels:

I’ve provided her with a, a personal flow chart for Jack... if he’s low like between a certain um scale give him one sugar cube. If he’s this give him two, recheck him and as long as she sticks to that and follows the flow chart then he’ll be good as gold. (Participant 6, Mother: Son, 9 years).

Other parents have also described how teachers have provided support by maintaining regular communication during school or daycare hours to indicate the child’s blood sugar levels, and if the parent needs to attend school to do insulin injections. In these ways, by accommodating the child and the family’s needs, schools and daycare centres can contribute to parental resilience by helping parents in their daily ‘doing’ of diabetes.

All parents described the support they received from health care professionals. One of the underlying elements in this support was the empowering effect that health care professionals can have on the parents' ability to care for their child through education, as explained by the mother below:

...she empowered us to take control ...it's education that, that really, really empowers you to know but, but education at the right time, because you don't want to have everything overloaded to you when you're first diagnosed. So again it's that process and being able to have someone walk alongside you, that you can totally trust. (Participant 16, Mother: Son, 11 years).

Health professionals were seen as most supportive to parental coping when they regarded the parent as the expert and when they were able to establish a collaborative relationship with parents in managing the child's diabetes. One parent expressed "they get to know those kids and they get to know how they respond and what they tend to do and I feel um safer that way that, you know especially his consultant knows him quite well, you know and how, how tricky he can be and we negotiate together, we talk together when he needs help" (Participant 8, Mother: Son, 12 years). Support by the health care team was more inconsistent in rural areas due to limited resources. Parents who had moved to more urban areas described the increase in support they had experienced from these larger services.

Parents also described how connecting with other parents with children with Type 1 diabetes helped them in their coping. This provides a space for making meaning out of the shared adversity which could be empowering for these parents. One mother commented: "so I think for me...the three mothers that I've met and connect, and really clicked with, um, it's awesome having them... they're big allies" (Participant 5, Mother: Daughter, 9 years). This mother's use of the word 'allies' denotes the support inherent in a shared cause or purpose in a mutual battle. Parents also described the support they received by initiatives such as diabetes camps organised by the local Diabetes Trust, in providing respite from daily management and bringing parents together. For some parents, taking an active role in raising diabetes awareness in the community was a crucial way of coping with their child's illness.

Discussion

This study explored experiences of resilience described by parents of children with Type 1 diabetes to understand the ways in which they adjust and cope with the demanding caregiving role. It has highlighted the complexities in understanding the concept of resilience. The findings indicate a mismatch between parents' talk of what

it means to be resilient and how they practiced resilience. Parents generally drew on the mainstream psychological understanding of resilience as something residing in them. This could be due to the ways that psychological research has talked about resilience that had permeated into the public consciousness, shaping lay understandings. Parents' accounts presented an alternative way of understanding resilience as 'doing resilience' – the everyday practices of coping with childhood diabetes. This goes beyond a simple dichotomy of resilient versus non-resilient, challenging much of the resilience literature. 'Doing' resilience demonstrates the dynamic nature of resilience and offers a more meaningful way of understanding the concept in this particular context.

Rather than extraordinary events or characteristics, this analysis of parents' experiences demonstrates that parental resilience is enacted through their daily work of caring for their child with diabetes. This shifts the focus from the individual to the actions and behaviours that they perform daily. Attention to the everyday aspects is highly relevant with Type 1 diabetes, with its unremitting chronic nature. Like Hatala and colleagues' (2013) findings on how daily living involved acts of resilience in the context of individuals living with disability, 'doing' resilience involved parents' accounts of everyday coping which supported their wellbeing while they persevered in their daily efforts to provide the best care possible for their child with diabetes. Parents used several strategies in this process, which involved at times focusing on coping better in the future. This demonstrates how resilience does not exist as a static quality or mechanistic process, but on a continuum that varies over time and context (Nyugen-Gillham, Giacaman, Naser, & Boyce, 2008).

The analysis also highlighted the significance of separating actions from emotions in helping parents cope with the daily demands of diabetes. 'Doing' diabetes takes precedence over managing emotions on a daily basis, although parents expressed a need for emotions to be tended to at the right times when they have the time and space to deal with them. This indicated that a behavioural approach to coping and wellbeing was more useful for the parents in this study. The preference for actions over emotions appears to be consistent with the prominent theoretical model of coping (Lazarus & Folkman, 1984), which makes a distinction between problem-focused coping and emotion-focused coping. The increased focus on behaviours compared to emotions challenge current psychological approaches that work to enhance emotion-focused coping, such as emotion coaching (Greenberg, 2004).

The parents' practice of resilience was supported by several processes. Parents' acceptance of the condition was a complicated process where parents negotiated their

need to resign to the reality of living with diabetes with the need to keep alive hope for a cure. This finding is consistent with previous research which suggests that parents may never reach an end-point of acceptance as proposed by time-bound models of grief (Lowes & Lyne, 2000). Several parents derived strength from spirituality in coping with their everyday challenges. Parental accounts of how spirituality helps them indicate a personal and highly individualised way of negotiating hardship. This meaning making process help parents move from a place of resignation to interpreting their experience as having a wider meaning, to make sense of the 'why us' of diabetes. Both acceptance/resignation and spirituality were processes that involved dealing with emotional reactions, to create space for the daily 'doing' of diabetes. Parents also highlighted how their everyday coping was supported by the wider systems of family, friends, other parents, and health professionals, consistent with past findings (Whittemore et al., 2012). These findings indicate the social and contextual dimension of resilience, highlighting how the particular environment has the ability to foster parents' performance of resilience.

The findings of the current study carry several implications for health professionals. In general, it increases the awareness of parents' experiences so that services can better support parents. In particular, it emphasises how a focus on individual attributes or factors cannot help parents in their coping with the everyday demands of caring for a child with Type 1 diabetes. Parents can be encouraged to recognise their 'doing' of resilience through their highly individualised ways of coping with the everyday demands of diabetes. It suggests moving away from understanding resilience in terms of outcomes and focusing on the practical realities of these parents, where parents focus on coping one day at a time. These results indicate the importance of how health professionals conceptualise resilience in their interactions with parents, where a focus should not be on 'being' resilient, but rather how they can better support them in their everyday work of 'doing' resilience. This shift in understanding of resilience from the individual to the person-in-context can help foster resilience by making it a collective responsibility. For example, parents' accounts indicate that they experience difficulties with accessing more on-going psychological support which would help parents with managing their emotions at meaningful times, indicating an area that can be addressed by services, in improving parental coping.

The present study provided a useful area to examine the concept of resilience, as the adversity of diabetes in a child presents constant and on-going challenge with little relief for parents. The use of IPA in this study provided an opportunity to place the parents' accounts within the wider social, cultural and theoretical context (Larkin, Watts, & Clifton, 2006). This allows a more critical analysis of the parental accounts of

resilience by drawing attention to the influences that shaped their sense-making, such as the dominant conceptualisations of resilience. The fact that parents were not specifically asked to comment about resilience presents a particular strength of the study, as this may have compelled them to answer in ways that positioned themselves as either having or not having resilience. However, the findings of the present study should be interpreted with caution as it did not explore how socioeconomic factors such as poverty can make it difficult for parents to 'do' resilience. Future research could further explore how supportive environments can foster resilience for parents caring for children with chronic conditions. Using different research methods such as ethnography or narrative research can also contribute to further perspectives in this area.

Conclusion

Understanding how parents cope with a chronic illness in a child can have important implications for the wellbeing of both the child and the parents. The present study portrays experiences of resilience described by parents of children with Type 1 diabetes, by using IPA. While the initial intention of the research was to explore experiences of resilience within the families, it was found that parents' accounts revealed a more personal experience than one which represented the entire family. Parents' descriptions of resilience mirrored the common conceptualisations of resilience as a characteristic residing in themselves. However, parents were seen to be 'doing' resilience, inherent within their everyday acts of parenting their child with Type 1 diabetes. The current study also highlighted the role of actions over emotions in the everyday coping of parents and how 'doing' resilience was fostered by processes that helped parents to focus on the daily 'doing' of diabetes. Parents used the processes of acceptance and resignation, spirituality and social support in augmenting this practice of resilience. These findings emphasise how reconceptualising resilience for these parents in this way could lead to a more realistic understanding of their coping processes by taking into account the social and contextual dimensions of resilience. These findings also present important implications for health professionals in how they understand and apply the concept of resilience in their work with these parents. This research also adds to the body of literature on parental experiences of chronic childhood conditions.

References

- Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11-18. doi:10.1093/heapro/11.1.11
- Aranda, K., Zeeman, L., Scholes, J., & Morales, A. S-M. (2012). The resilient subject: Exploring subjectivity, identity and the body in narratives of resilience. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 16*(5), 548-563. doi:10.1177/1363459312438564
- Anderson, K. M. (2010). *Resilience in survivors of family violence*. New York, NY: Springer Publishing Company.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219-234. doi:10.1177/1468794112468475
- Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 25*(5), 533-543. doi:10.1007/s10882-013-9333-5
- Bottrell, D. (2009). Understanding 'marginal' perspectives: Towards a social theory of resilience. *Qualitative Social Work, 8*(3), 321-339. doi:10.1177/1473325009337840
- Buckloh, L. M., Lochrie, A. S., Antal, H., Milkes, A., Canas, J. A., Hutchinson, S., & Wysocki, T. (2008). Diabetes complications in youth. *Diabetes Care, 31*(8), 1516-1520. doi:10.2337/dc07-2349
- Coyle, J. P. (2011). Resilient families help make resilient children. *Journal of Family Strengths, 11*(1), 1-16.
- de Boer, I. H., Rue, T. C., Cleary, P. A., Lachin, J. M., Molitch, M. E., Steffes, M. W., . . . Brunzell, J. D. (2011). Long-term renal outcomes of patients with Type 1 diabetes mellitus and microalbuminuria: An analysis of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications cohort. *Archives of Internal Medicine, 171*(5), 412-420. doi:10.1001/archinternmed.2011.16
- Doyle, E. A., & Grey, M. (2010). Diabetes mellitus (types 1 and 2). In P. J. Allen, J. A. Vessey & N. A. Schapiro (Eds.), *Primary care of the child with a chronic condition* (5th ed.). St. Louis, Missouri: Mosby Elsevier.

- Driscoll, K. A., Johnson, S. B., Barker, D., Quittner, A. L., Deeb, L. C., Geller, D. E., . . . Silverstein, J. H. (2010). Risk factors associated with depressive symptoms in caregivers of children with Type 1 diabetes or cystic fibrosis. *Journal of Pediatric Psychology, 35*(8), 814-822. doi:10.1093/jpepsy/jsp138
- Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 179-194). Los Angeles: Sage Publications.
- Garmezy, N. (1991). Resiliency and vulnerability to adverse developmental outcomes associated with poverty. *American Behavioral Scientist, 34*(4), 416-430. doi:10.1177/0002764291034004003
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997. doi:10.1111/j.1365-2788.2009.01220.x
- Greenberg, L. S. (2004). Emotion-focused therapy. *Clinical Psychology & Psychotherapy, 11*(1), 3-16. doi:10.1002/cpp.388
- Gudmundsdottir, E., Schirren, M., & Boman, K. K. (2011). Psychological resilience and long-term distress in Swedish and Icelandic parents' adjustment to childhood cancer. *Acta Oncologica, 50*(3), 373-380. doi:10.3109/0284186X.2010.489572
- Harvey, M. R. (2007). Towards an ecological understanding of resilience in trauma survivors. *Journal of Aggression, Maltreatment & Trauma, 14*(1-2), 9-32. doi:10.1300/J146v14n01_02
- Hatala, A. R., Waldram, J. B., & Crossley, M. (2013). Doing resilience with "half a brain:" Navigating moral sensibilities 35 years after hemispherectomy. *Culture, Medicine and Psychiatry, 37*(1), 148-178. doi:10.1007/s11013-012-9294-7
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindermann, E., & Grey, M. (2008). Mediators of depressive symptoms in children with Type 1 diabetes and their mothers. *Journal of Pediatric Psychology, 33*(5), 509-519. doi:10.1093/jpepsy/jsm104
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindermann, E., & Grey, M. (2009). Coping and psychosocial adjustment in mothers of young children with Type 1 diabetes. *Children's Health Care, 38*(2), 91-106. doi:10.1080/02739610902813229

- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. doi:10.1191/1478088706qp062oa
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lenette, C., Brough, M., & Cox, L. (2012). Everyday resilience: Narratives of single refugee women with children. *Qualitative Social Work*, 12, 637-653. doi:10.1177/1473325012449684
- Lowes, L., & Lyne, P. (2000). Chronic sorrow in parents of children with newly diagnosed diabetes: A review of the literature and discussion of the implications for nursing practice. *Journal of Advanced Nursing*, 32(1), 41-28. doi:10.1046/j.1365-2648.2000.01418.x
- Lowes, L., Lyne, P., & Gregory, J. W. (2004). Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*, 21(6), 531-538. doi:10.1111/j.1464-5491.2004.01193.x
- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543-562. doi:10.1111/1467-8624.00164
- Massey, S., Cameron, A., Ouellette, S., & Fine, M. (1998). Qualitative approaches to the study of thriving: What can be learned? *Journal of Social Issues*, 54(2), 337-355. doi:10.1111/j.1540-4560.1998.tb01222.x
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56(3), 227-238. doi:10.1037/0003-066X.56.3.227
- Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with Type 1 diabetes. *Children's Health Care*, 36(4), 385-396. doi:10.1080/02739610701601403
- Nguyen-Gillham, V., Giacaman, R., Naser, G., & Boyce, W. (2008). Normalising the abnormal: Palestinian youth and the contradictions of resilience in protracted conflict. *Health & Social Care in the Community*, 16(3), 291-298. doi:10.1111/j.1365-2524.2008.00767.x
- Oskouie, F., Mehrdad, N., & Ebrahimi, H. (2013). Mediating factors of coping process in parents of children with type 1 diabetes. *Journal of Diabetes and Metabolic Disorders*, 12, 1-7. doi:10.1186/2251-6581-12-20

- Pop-Busui, R., Low, P. A., Waberski, B. H., Martin, C. L., Albers, J. W., Feldman, E. L., . . . Herman, W. H. (2009). Effects of prior intensive insulin therapy on cardiac autonomic nervous system function in Type 1 diabetes mellitus: The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study (DCCT/EDIC). *Circulation*, *119*(22), 2886-2893. doi:10.1161/CIRCULATIONAHA.108.837369
- Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, *58*(3), 307-321. doi:10.1002/jclp.10020
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, *57*(3), 316-331. doi:10.1111/j.1939-0025.1987.tb03541.x
- Seppänen, S. M., Kyngäs, H. A., & Nikkonen, M. J. (1999). Coping and social support of parents with a diabetic child. *Nursing and Health Sciences*, *1*, 63-70. doi:10.1046/j.1442-2018.1999.00009.x
- Smith, J. A., & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in Psychology* (pp. 35-50). Los Angeles: Sage.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53-80). London: Sage.
- Streisand, R., Mackey, E. R., & Herge, W. (2010). Associations of parent coping, stress, and well-being in mothers of children with diabetes: Examination of data from a national sample. *Maternal and Child Health Journal*, *14*, 612-617. doi:10.1007/s10995-009-0497-7
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing*, *18*(1), 21-29. doi:10.1053/jpdn.2003.4
- Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, *7*(2), 213-225. doi:10.1348/135910702169457
- Ungar, M. (2008). Resilience across cultures. *British Journal of Social Work*, *38*, 218-235. doi:10.1093/bjsw/bcl343
- Ungar, M. (2003). Qualitative contributions to resilience research. *Qualitative Social Work*, *2*(1), 85-102.

- Ungar, M. (2004). A constructionist discourse on resilience: Multiple contexts, multiple realities among at-risk children and youth. *Youth & Society, 35*(3), 341-365. doi:10.1177/0044118x03257030
- Ungar, M., Brown, M., Liebenberg, L., Othman, R., Kwong, W. M., Armstrong, M., & Gilgun, J. (2007). Unique pathways to resilience across cultures. *Adolescence, 42*(166), 287-310.
- Ungar, M., & Liebenberg, L. (2005). The International Resilience Project: A mixed-methods approach to the study of resilience across cultures. In M. Ungar (Ed.), *Handbook for working with children and youth: Pathways to resilience across cultures and contexts* (pp. 211-226). Thousand Oaks: SAGE Publications.
- Werner, E. E., & Smith, R. S. (1992). *Overcoming the odds: High risk children from birth to adulthood*. London: Cornell University Press.
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with Type 1 diabetes. *The Diabetes Educator, 38*, 562-579. doi:10.1177/0145721712445216
- Whittemore, R., Urban, A. D., Tamborlane, W. V., & Grey, M. (2003). Quality of life in school-aged children with type 1 diabetes on intensive treatment and their parents. *The Diabetes Educator, 29*(5), 847-854. doi:10.1177/014572170302900514
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215-228. doi:10.1080/08870440008400302
- Zalewska, A., Miniszewska, J., Chodkiewicz, J., & Narbutt, J. (2007). Acceptance of chronic illness in psoriasis vulgaris patients. *Journal of the European Academy of Dermatology and Venereology, 21*(2), 235-242. doi:10.1111/j.1468-3083.2006.01912.x



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**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Fathimath Rifshana

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Name of Published Research Output and full reference:

Making Sense of Hardship: Exploring Resilience in the Parental Experience of Caring for a Child with Type 1 Diabetes

In which Chapter is the Published Work: Chapter 5

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or

- Describe the contribution that the candidate has made to the Published Work:

The candidate is responsible for the analysis and write-up of the manuscript. The supervisors contributed to the manuscript by providing guidance on structuring arguments and the clarity of the write-up.

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CHAPTER 6: DISCUSSION

The findings of the current study presented across the three previous chapters described different aspects of the overall parental experience of caring for a child with Type 1 diabetes. The first paper concentrated on explicating issues of embodiment in the caregiving experience, while the second paper described the impact on parental identity. The third paper explored the concept of resilience in the parental experience. The first two papers highlighted the challenges and impact of the illness, as a focus on resilience alone could create a risk that some of the parents' more difficult experiences could be missed. A similar finding was reported in a study of family resilience in families with a parent with mental illness (Power et al., 2016). The authors found that both positive and negative stories of family life were intermingled, suggesting that a sole focus on positive experiences would not capture their overall experience. Etchegary (2010) emphasise how the experience of chronic illness should "not be dichotomised into 'loss and suffering' on the one hand, with 'transforming and positive' on the other" (p.646). Suffering and thriving could be better conceptualised as a braided process (Massey, Cameron, Ouellette, & Fine, 1998). This finding was highlighted in the current study where accounts of struggle appeared alongside parents' stories of coping, revealing the tensions and complexity inherent in their experiences of caregiving. This finding also resonates with that of Carnevale and colleagues (2006), who described the irreconcilable tension between the distresses and enrichments involved in caring for a child requiring assisted ventilation at home. Overall, these findings support the notion that caring for a child with a chronic illness is a multifaceted experience involving both losses and gains, and that both play important roles in parents' meaning-making processes.

The current study also demonstrated the significance of embodiment in the parental experience of caring for a child with Type 1 diabetes. Embodiment can be described as the sense of living in and through our bodies (Tolman, 2005). Glenberg (2010) asserts embodiment as a unifying perspective for psychology, which can facilitate the exploration of processes nestled within the dynamic interactions of behaviour, bodily processes, and changes in the physical and social world. The current study contributes to the limited literature on embodiment within childhood diabetes by exploring the processes of embodiment to reveal the extent of parents' physical and emotional engagement with their child's body. As our cultural, social, and emotional knowledge and experiences are lived through the body (Sharma, Reimer-Kirkham, & Cochrane, 2009), these manifestations of embodiment tell the stories of the parents' lives, providing a rich insight into their lived experience. Parent's experience of being in the

world was irrevocably changed by the diagnosis of diabetes. Constant vigilance dominated this experience, and parents engaged in social practices of nuanced strategies to manage the unpredictability that diabetes entailed. Parents' attunement with their child's body was central to the maintenance of their children's health. These findings support the call to "bring the body back in" to caring research and practice (Sakalys, 2006).

The second main theme described the impact on parental identity following the diagnosis of Type 1 diabetes. Although the themes were examined separately, connections can be seen between parental identity and issues of embodiment. These highlight the interrelations between the two aspects and the salience of these elements to their caregiving experience overall. Parental identity was closely related to the embodied practices of parenting work. The unpredictable nature of diabetes challenged parental identity through undermining their confidence in adequately caring for the child and ensuring their secure future. The interplay between parental identity and the embodiment of a child was also highlighted by Kelly (2005). Parents were described as representatives for their child with an impairment, within the ongoing social and cultural contexts. Parents' sense of self were intimately connected to the ways that they presented the child to the world, such as through grooming and adorning, to achieve an ethical ideal of social acceptance for their child. For the parents in the current study, their parental identity was related to their ability to care for their child. In the medical and social context, glycaemic control can be the standard against which this caring is judged. The unpredictability of glycaemic control, an important part of the embodied experience, can thus undermine their parental identity.

Similarly, links between parental identity and resilience can be examined. Parents' coping through the enactment of resilience emerged out of the significant biographical disruption when the illness occurred. The diagnosis brought their life to a halt in various ways, challenging their parental identity. 'Doing' resilience involved processes that parents engaged in to enable everyday coping with the daily demands of diabetes. These highlight the intersection between the impact on their identity and coping. Parents are engaged in re-making their identities by pursuing normality. This can also be seen as another act of resilience and everyday coping that helped them in promoting the wellbeing of not just themselves, but the entire family.

Parents' everyday coping involved processes such as their focus on 'doing' diabetes. The coping strategies described by parents in the current study are consistent with previous findings. Parents' descriptions of 'doing' diabetes resonate with those of the

fathers in Sullivan-Bolyai and colleagues' study of being a father of young children with Type 1 diabetes (2006). Fathers described having to "suck it up and do it", referring to diabetes care. In addition, parents' use of spirituality in accepting diabetes has also been previously described (de Oliveira, Nascif-Júnior, & Rocha, 2010). Religion is often mentioned as a coping strategy within childhood chronic conditions (Atkin & Ahmed, 2000). Parents in the current study highlighted the important role of health professionals, family, and friends, in augmenting their coping, which is also consistent with past research (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). In these ways, the findings of the current study add to the growing body of literature on parental experiences in the context of childhood diabetes, and also other chronic childhood conditions in general.

Implications of Findings for Clinical Practice

The current study presents important findings in light of the growing incidence of Type 1 diabetes in children (International Diabetes Federation, 2015). They enhance the understanding of what it is like to be a parent of a child with Type 1 diabetes, which can help professionals to provide more empathic and sensitive support. A better understanding of the often overwhelming demands on these parents is critical in establishing supportive relationships with them, when working together in the best interest of their child. Recognition of the impact of the illness on the parents' lives is paramount when developing supportive strategies for them. The important role of health care professionals in being able to normalise and validate parents' experiences, and enabling them to cope in the context of childhood diabetes and other chronic conditions is thus highlighted.

The findings of the current study indicated that constant vigilance is a key experience of parents caring for a child with Type 1 diabetes. Vigilance has also been described by parents caring for children with other conditions, such as food allergy and autism (Rouf, White, & Evans, 2011; Woodgate, Ateah, & Secco, 2008). However, the experience of vigilance is likely to be different across conditions. Parents of children with severe food allergy described that their vigilance dropped when long periods elapsed after an allergy reaction. The findings of this study indicated that for parents of children with Type 1 diabetes, vigilance can stay consistently high, as they need to continue monitoring of blood glucose, insulin and activity levels, on a daily basis. This was made more complicated by how parents found it difficult to find alternative caregivers who understood the complexity of and the clinical management of the condition. This means that parents receive little relief from their caregiving responsibilities. The lack of relief has been shown to lead to social isolation in parents

of children with chronic conditions (Woodgate et al., 2008). Health practitioners working with parents can find ways of supporting parents with taking respite. This could involve assisting parents in finding suitable caregivers or educating caregivers, so they are able to adequately care for the child in the absence of the parents.

The results of the current study can also help health professionals become more aware of the ways that parents cope with childhood diabetes. Parents emphasised the importance of normality in coping with the illness, which is consonant with past research in childhood chronic conditions. Parents of children with autism have described how maintaining some level of routine family life helped them achieve a sense of normalcy (Woodgate et al., 2008). Similar findings were described by parents of children with sickle cell disorder or thalassaemia, who emphasised normal aspects of the child's life, to minimise the impact of the condition (Atkin & Ahmed, 2000). They highlighted how the ability to compartmentalise the consequences of these illnesses, such as through receiving blood transfusions at the hospitals and using infusion pumps usually in the evenings, enhanced a normal life for the child. Parents in the current study pursued normality by providing the child with typical childhood experiences, adjusting to a new normality, and adhering to a family normality. Symons (2013) asserted that parents in her study also came to terms with a 'new normal'. Health professionals working with parents can understand these ways of pursuing normality as an important part of the parents' adjustment to the illness, and assist parents in sustaining this coping strategy, rather than keeping a focus on strict blood sugar control.

The findings of the current study also indicated that parents and children need more on-going formal emotional support, consistent with past research (Bowes, Lowes, Warner, & Gregory, 2009; Lowes, Eddy, Channon, McNamara, Robling, & Gregory, 2015; Rankin & Lawton, 2015). While the clinic appointments every three months are vital for the clinical management of the condition, parents' accounts indicate that this is insufficient to deal with the significant psychosocial impact of the illness. As clinic appointments occur in the presence of the child, parents may be reluctant to discuss their emotional difficulties during this time (Whittemore, Jaser, Chao, Jang, & Grey, 2012). Some parents in the current study were unaware of the available psychological support, or had forgotten that such information was provided at the time of diagnosis, as they were trying to adjust to the news of the diagnosis. This indicates that routinely asking parents about how they are coping and reminding them about any available emotional support will be beneficial. These findings also highlight the need to integrate psychological support into routine diabetes care, as emphasised in the literature (Delamater, de Wit, McDarby, Malik, & Acerini, 2014; Ross, Malthus, Berrett, & Harvey,

2009). Based on 2012 data, only three DHB paediatric diabetes sites in New Zealand include a psychologist within the treatment team, indicating a shortage of resources to deal with the increasing incidence of Type 1 diabetes (Jefferies, Owens, & Wiltshire, 2015). Provision of routine psychological support can assist parents and children with their emotional functioning and ultimately their adjustment to Type 1 diabetes.

The findings also raise important themes to include more parental perspectives within existing clinical guidelines of childhood diabetes. The results of the current study highlighted parents' difficulties in maintaining glycaemic control within recommended targets, and their need to balance illness demands with normal family life. A discourse analysis of Swedish, Danish, and Norwegian health care guidelines for children with Type 1 diabetes found the centrality of an expert discourse (Boman, Borup, Povlsen, & Dahlborg-Lyckhage, 2012). This discourse positioned parents as dependent on experts for scientific knowledge and may undermine parents' voice, knowledge and skills. By providing opportunity for parents to voice their experiences when developing such guidelines, more realistic recommendations can be developed to reflect parents' lived experiences of caring.

Overall, the findings of the current study demonstrate the meanings that parents assign to their experiences, which can assist health professionals gain a better understanding of parents' lived experiences. Health professionals can use this knowledge in working with parents to supplement their coping, to minimise the impact and degree of disruption caused by a diagnosis of Type 1 diabetes in a child.

Methodological Considerations

A qualitative approach in general allowed parents to voice what it was like to care for their child with Type 1 diabetes, adding to the small but growing body of literature in this area. A strength of the current study was the use of IPA allowing an in-depth exploration of parental experiences. IPA enabled the analysis to go beyond simple description and critically analyse the different ways that parents made sense of their experiences. IPA also proved ideal to explore parental accounts with its emphasis on embodied experience (Langdrige, 2008), given the implications of embodiment within parents' daily experience. Additionally, its focus on anchoring parents' experiences within social, cultural, and theoretical contexts made it particularly suitable (Callary, Rathwell, & Young, 2015). Parents' constant vigilance and surveillance of their child reveal their socially situated experiences of parenting, where this vigilance is driven by the focus on maintaining good glycaemic control, within a context of multiple factors that can make this difficult to achieve. These highlight the inherent social context and

situations where parenting naturally occurs. Parents' pursuit of normality through typical childhood experiences showed what it meant to them to have a typical childhood in New Zealand, thereby exposing cultural influences that shaped their lived experience of caregiving. Exploring experiences of resilience also provided an opportunity to challenge existing theoretical constructs of resilience, to propose a more contextually relevant conceptualisation of resilience for these parents. Hence, the use of IPA provided a critical exploration of parental experiences of caregiving in relation to wider influences that shaped their sense-making.

The benefits of using IPA in this study will need to be balanced with a consideration of limitations of this approach. A conceptual limitation of IPA relates to the role of language (Willig, 2001). As IPA works with descriptions provided by participants, language plays a vital role in relating their experiences to the researcher. However, it can be argued that language constructs a particular version of experience and therefore does not provide direct access to the actual experience itself (Willig, 2001). Another limitation of IPA concerns how IPA is able to provide detailed descriptions of participants' experiences, but is unable to explain *why* such experiences happen and the reasons for the differences in individuals' experiences (Willig, 2001). As IPA is concerned with an individual's perception or account of a topic, it does not attempt to predict future behaviour or make assumptions about differences in behaviour. Applied to the current study, this limitation means that IPA is unable to predict which particular contexts or conditions make it easier or harder for parents to care for a child with Type 1 diabetes. The advantages provided by IPA for this study will thus need to be considered in light of these limitations inherent in the approach.

In addition to the value provided by IPA in this study, this research was also strengthened by the researcher being independent from any treatment teams and being based in a psychosocial perspective. This provided an opportunity for the parents to report their experiences of parenting a child with a health condition to someone outside their health care team. Some parents in the study commented that this was the first time that they had discussed their personal experiences of caring for their child with someone outside of the immediate family or friends. One parent even highlighted the therapeutic nature of the interview itself. In addition, there were no specific questions asked about the child's metabolic control, such as their last HbA_{1c} rating, which created a non-judgemental space for the parents to discuss their experiences and concerns. Health care visits are often focused on reporting of HbA_{1c} results and developing strategies that will improve results. Parents have described feeling like a failure when their child does not achieve the recommended target (Lowe et al., 2015). Hence, the research findings have been enhanced by the researcher's

position outside the treatment team and by a stronger focus on psychosocial aspects of parents' experiences.

Data collection was also strengthened by the setting of the interviews. All interviews except one were carried out at parents' homes, which provided a more naturalistic and familiar environment for them, and allowed them to tend to their children's needs (and most importantly carry on with diabetes management). This meant that some interviews occurred in the presence of the child with diabetes or other children. This could have influenced what the parents shared about their experiences, such as leaving out more distressing aspects of their experience. Nevertheless, one parent acknowledged worries about long-term complications (blindness and amputations) in the presence of the child with diabetes (aged 12), indicating that some parents may be quite open about discussing more serious concerns in front of their children depending on their age.

Another strength of the study involved the recruitment strategy. The study included parents from three geographical areas, each reflecting different resourcing and support available from the local DHBs and the local community. This provided diversity in parental experiences and perspectives that were shaped by different structural and contextual factors that influenced parents' coping processes. As an example, one parent from Hawke's Bay commented on the opportunity for Palmerston North residents to drop used needles at the waste disposal station, wishing that such a service was available for them to ease their workload. Some parents in Hawke's Bay had also changed from the local DHB diabetes service to a general practitioner with special interest (GPSI) in diabetes working from a patient-centred approach, which had a positive impact on their management of their child's condition and their own coping with the condition. Another parent from Whanganui emphasised how the lack of a permanent paediatrician caused them difficulty with on-going clinical management. Parents and children with diabetes living in Palmerston North and surrounding districts were fortunate to receive additional support through the Youth Coordinator from Manawatu Horowhenua Tararua Diabetes Trust. This support has now been extended to include Whanganui region. The availability of support by diabetes services in educating school personnel can also impact on parents' experiences, as it can ease the burden of informing the appropriate guidelines by the parents themselves. In such ways, the available support within their social environment had a differential impact on the experience of caring for their child with Type 1 diabetes.

The recruitment process may also have influenced the findings of the study in particular ways. In the public materials, the study was titled 'family resilience in

childhood diabetes'. Parents who self-selected into the study could have identified themselves as particularly resilient. This could mean that the experiences of parents explored in this study may be quite different to those who decided not to participate, for any reason. The idiographic nature of IPA also means that the results of the study cannot be generalised to the wider group of parents with a child with Type 1 diabetes. The conclusions drawn are specific to this group of individuals studied. Idiographic inquiry is committed to exploring understandings that are located within their particular social reality and situation (Biggerstaff & Thompson, 2008). The idiographic focus allowed for the analysis of intricacies in individual accounts, illuminating the life world of the particular participants who shared their stories leading to a deep and situated analysis of the parents' experiences (Smith, 2004).

A further consideration that arose from the recruitment process is that most of the participants in this study were mothers, and most of these mothers took on the primary responsibility for diabetes care. This may reflect the finding that in New Zealand, mothers generally spend more time caring for children than fathers (Statistics New Zealand, 2013). Only one study has been identified that solely explored the experiences of fathers parenting children with Type 1 diabetes (Sullivan-Bolyai, Rosenberg, & Bayard, 2006). This study indicated how fathers' experiences can be different from mothers'; for example, fathers tended not to discuss difficult emotions for various cultural and societal reasons. Hearing accounts from more fathers could provide an opportunity to examine differences in the embodied experience between mothers and fathers. Further research involving more fathers could contribute to enhanced knowledge on their perspectives and experiences that may be different from mothers.

Another limitation of the recruitment process involved the lack of ethnic diversity in the study sample, making it difficult to generalise the research findings. The majority of the participants had described themselves as New Zealand European (15 out of 17). Only one participant had identified themselves as New Zealand Māori. One possible reason for this lack of diversity in the sample is that in New Zealand, the incidence of Type 1 diabetes is higher among children of European-origin than their Māori and Pacific Islander peers. In a review of Type 1 diabetes incidences in the Auckland region for the period 1990-2009, in children under the age of 15 years, the annual incidence per 100,000 among European-origin children was 32.5 compared to 13.9 among children of Māori ethnicity and 15.4 among children of Pacific Island ethnicity (Derraik, Reed, Jefferies, Cutfield, Hofman, & Cutfield, 2012). Another likely reason for the lack of Māori or Pacific Islander representation in the sample could reflect the ways that participants were recruited. Even though a Kaumatua was consulted prior to

recruitment and data collection, the lack of the study being publicised through local networks of Maori and Pacific Island community could have limited their participation (Health Research Council, 2010).

A further methodological consideration is that, the current study did not use member checking as a method of establishing the credibility of its findings. Member checking is the process of taking the results of the analysis back to the participants to check if the overall account is realistic and accurate (Creswell & Miller, 2000). While participants were sent a copy of the transcript of their interviews as requested (none were returned with changes), and some preliminary findings, no follow-up interviews were carried out to discuss the final results. The use of member checking within interpretive qualitative research has been a subject of debate. It is argued to be incongruent with the hermeneutic phenomenological philosophy, as the concern with the 'right' interpretation violates the principle of multiple truths espoused by the tradition (McConnell-Henry, Chapman, & Francis, 2011). The findings presented in the study are the researcher's interpretation of parental accounts which will differ from another person's reading of the data. There was a risk that parents could feel unsure about what they have expressed possibly prompting them to change their minds about issues. In addition, making parents revisit the issues from the first interview may potentially be an unpleasant experience, as they may not have the time or energy to ensure that the researcher has achieved the 'right' interpretation (McConnell-Henry et al., 2011). Hence, a follow-up interview to discuss final results was deemed inappropriate for the current study. Participants were advised that a copy of the final results will be sent to them at the conclusion of the study.

Lastly, the study has undergone considerable change in focus since the initial development of the topic. An earlier focus on family resilience in childhood diabetes became an investigation into individual resilience. In addition, the focus widened to include other experiences of parents, such as the issues of embodiment and the transition experience.

Reflexivity

The researcher is an inherent part of both the process and product of research (Horsburgh, 2003). Reflexivity has been described as self-appraisal in research, where the researcher recognises their situatedness within the research and the impact they may have on the research process and outcome (Berger, 2015). Being reflexive involves being aware of how the research topic relates to one's self, positioning oneself in the social space where they come from and recognising the lenses through

which one views their position (Hamdan, 2009). To this end, I provide the following descriptions of myself and how I believe these characteristics influenced the research endeavour.

I am a married woman in my 30's pursuing a Doctorate in Clinical Psychology. In my late 20's, I worked as a teacher aide at a local primary school, assisting children with different developmental conditions. During this time, I worked closely with parents in helping children participate in programmes at this mainstream school. My interest in chronic conditions of childhood and its impact on families remained with me as I pursued postgraduate studies and led me to develop this study. Once I had narrowed down the focus to explore experiences of parenting a child with Type 1 diabetes, I wanted to draw attention to the range of experiences of adjustment to the illness without being constrained by any predetermined notions of adjustment and coping. In this sense, the choice to use IPA suited my epistemological stance to the research. I was constantly mindful of treating each parent as a unique individual with a unique perspective worthy of investigation.

I am also a South-East Asian who immigrated to New Zealand. Although I can speak and write English well, and have lived in New Zealand for longer than 10 years, this characteristic still places me in a relative minority within my new home. Having personal experiences of being a minority, I have always had an interest in exploring under-researched populations and topics. My choice of exploring the experiences of parents caring for children with Type 1 diabetes, an under-represented group, was shaped by these motives.

My particular interest in the concept of resilience arose during a time of family distress following the death of a close family member. This meant that understanding how individuals and families cope through adversity, such as the bereavement of a loved one, had personal significance to me. I was keen to explore why this notion appealed to individuals experiencing difficulty in their lives and the different understandings that exist. I was aware that I had put on this particular lens when I applied this concept to understanding the lived experiences of parents caring for a child with Type 1 diabetes in this study. In these ways, I am able to reflect on my personal biography that have played a role in the development of the research area and topic.

My background as a clinical psychology doctoral candidate is also likely to have shaped the processes of research. It may have allowed the participants to open up more to me and may have influenced the type of experiences they shared with me. Parents may have shared the more distressing aspects of their experience that they may not

normally discuss with other health professionals. At certain points during the interviews, I was aware of a pull towards the role of a therapist (as I was a trainee psychologist at the time), yet I had to be mindful of my capacity as a researcher in that situation. My clinical psychology background did influence the findings, in that I wanted to highlight the most salient themes that would have an impact on clinical practice.

I am a mother of two young children. I was already a mother to one child when I carried out the interviews, a fact I disclosed in my introduction to the parents. This was helpful with building rapport with them, especially the mothers, as I was able to relate to some of their general parenting experiences. The fact that parents noted the parallels between having a new baby and having a child diagnosed with Type 1 diabetes demonstrate that parents took the opportunity to describe this experience to me in a way that I could relate to, as I have also experienced the significant transition of becoming a new parent myself. I could identify with the level of physical and mental engagement required in their new caregiving role. Further, being a mother of a young child allowed me to be empathic and understanding of the challenges that come with the early years of parenting. The attribute of being a mother thus influenced all stages of the research, from developing the research question to the data analysis, as I was able to relate with a range of experiences of the parents, such as their caregiving responsibilities and coping strategies.

I do not have a child with Type 1 diabetes nor knew any children with Type 1 diabetes before I commenced this project. However, my youngest son was diagnosed with a chronic respiratory condition during the write-up of the study. This felt like a process where I moved from the position of an 'outsider' to the position of an 'insider' in some respects, which are concepts explained by Berger (2015). I now had a child with a chronic childhood condition, even though it was not diabetes. This insider position granted me access to parents' experiences as I went through the throes of knowing something was wrong, uncertainty in diagnosis, the actual diagnosis and the grief that ensued. I was able to draw parallels between the daily demands of such an illness, their impact on the family, and how these needed to fit into family life. This coloured the way I perceived adjustment to a chronic illness, in that it is not a crossing of a 'line in the sand', and that it is very much an on-going process.

This change in status illuminates how my worldview changed over the course of the study. I was initially keen to explore how some families appeared to cope 'better' than others. However, through the process of engaging with the parents in the study, the phenomenological perspective that I took, and the personal experience of coping with

a chronic illness in a child, I came to understand the idiosyncratic nature of coping, the importance of context and understanding it from an individual's perspective. I realised the value in seeing coping as an embodied, on-going and intricate business. My understanding developed to go beyond an evaluation of outcomes in terms of 'better' or 'worse', in embracing the complexity and the multifaceted nature of the lived experiences of coping. The insider position during the data analysis phase thus helped illuminate the experiences and the nuanced descriptions of coping described by the parents in this study.

Upon reflection on the data analysis process, I recall being initially over-whelmed with the amount of data that was presented by the parents. I noticed a desire to report multiple themes and to ensure that the findings of the research represented the entire group. The final set of themes reported in the study are the ones that I judged as the most important in illuminating the research question. They were also the themes that resonated most with me, based on my characteristics and life experiences both as a mother and a health professional. As expressed by Hamdan (2009, p.379), the research process is "governed by the researcher's values and, reciprocally, these choices help to expose the values of the researcher".

In managing the practical difficulties I faced in completing the project, most often related to time pressures, I found it helpful to read entries I had made in my self-reflective diary. In some of these, I had reflected on how scarce research in this area was and how important it was to make sure this research was completed and published. I had emphasised on the importance of the research in standing up for and providing a voice for the participants in this study, and also for other parents caring for a child with a chronic condition.

Future Research

Exploring parental experiences of caring for very young children with Type 1 diabetes is a potential avenue for future research. Past research has shown that parenting this group of children with Type 1 diabetes is made more challenging due to issues such as the intrusive nature of the treatment regimen and difficulty with recognising early signs of hypoglycaemia, causing parents to be constantly vigilant and unable to take respite (Hatton, Canam, Thorne, & Hughes, 1995; Sullivan-Bolyai et al., 2003). Manifestations of embodiment or embodied practices can become evident in these experiences, such as parents co-sleeping with their young child to monitor them better. Exploring the concept of inter-embodiment (or intercorporeality) in this particular context can help extend the understanding of the ways in which parents

think and feel about their young children's bodies (Lupton, 2012). This can contribute to a deeper understanding of the intense nature of parenting a young child with a chronic illness.

Future studies could also include more family members to explore the family perspectives of having a child with Type 1 diabetes. Exploring the experience from this perspective can contribute to understandings of the implications of diabetes for all family members. For example, siblings of children with Type 1 diabetes have described being anxious and concerned about their brother or sister with diabetes, and not being able to eat whenever they felt like eating (Wennick & Hallström, 2006). Previous studies exploring family perspectives within childhood diabetes have done so using separate interviews with individual members. Interviewing the entire family together can result in rich accounts of family interactions. This can also provide valuable observational data. Families of adults living with Type 1 diabetes interviewed together have described their views on how diabetes impacted on their daily lives, their emotional reactions, and how they participated in the daily management of diabetes (Rintala, Paavilainen, & Åstedt-Kurki, 2013). Such knowledge gained from a collective perspective can help professionals working with families in providing support that takes into account other family member's needs and expectations as well.

Future research could also investigate the similarities and differences in the parental experience in caring for a child with Type 2 diabetes. While parent perceptions of caring for adolescents with Type 2 diabetes have been explored (e.g., Mulvaney et al., 2006), experiences of parents caring for children with Type 2 have not been previously studied. An increase in the prevalence of Type 2 diabetes in children and adolescents has been observed worldwide in the last two decades (D'Adamo & Caprio, 2011). The aetiology of Type 2 diabetes involves a complex interaction between genetic and environmental factors (Prasad & Groop, 2015). The rising rate of obesity worldwide has been attributed as a significant environmental factor. Parents of children with Type 2 diabetes could feel responsible and blamed for the diagnosis in their children due to this association of Type 2 diabetes with lifestyle choices. Future research could explore the impact on parental identity arising from the social implications of a diagnosis of Type 2 diabetes in a child.

Future investigations can also include the perspectives of health care professionals to explore their experiences in supporting parents of children with Type 1 diabetes. This can help gain insight into their roles in supporting parents, their understandings of parents' challenges, and their perceptions of how parents cope. Quirk, Blake, Dee and Glazebrook (2015) explored health professionals' perceptions of factors that influence

physical activity in children with Type 1 diabetes. They found that health professionals regarded parents as the main support for children in encouraging physical activity, and believed in their own role in promoting this activity while acknowledging barriers to this, such as time constraints and difficulty implementing physical activity guidelines. Clinician perspectives have also been explored in diabetes in adults on the role of empowerment and self-care (Scambler, Newton, & Asimakopoulou, 2014). It was found that empowerment was practiced within a bounded field, where success was still defined within a biomedical approach, and health professionals still appeared to hold control. Hence, exploring health professionals' views can enhance the understandings of the experiences of patients and their caregivers.

Conclusion

This research investigated the lived experience of parents caring for a child with Type 1 diabetes. Through in-depth analysis of parental accounts with IPA, the findings draw attention to the wide-ranging disruption this childhood condition can have on the parents' everyday lives. Findings demonstrate the inextricable nature of the embodied activity of parenting within the unpredictability posed by the illness. Parents' nuanced ways of coping was demonstrated by their strategies of comparison of Type 1 diabetes with other conditions and attempts at normality, which brought to light some of the social implications of the illness. Resilience for these parents was better regarded as an action rather than an individual attribute, which can be supported by ways that helped with the daily actions required of managing the health of their children. Understanding parents' experiences in more depth can contribute to knowledge that can enhance their coping and wellbeing, that of their family's, and ultimately their children's.

References

- Atkin, K., & Ahmad, W. I. U. (2000). Family care-giving and chronic illness: How parents cope with a child with a sickle cell disorder or thalassaemia. *Health & Social Care in the Community, 8*(1), 57.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219-234. doi:10.1177/1468794112468475
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5*(3), 214-224. doi:10.1080/14780880802314304
- Boman, Å., Borup, I., Povlsen, L., & Dahlborg-Lyckhage, E. (2012). Parents' discursive resources: Analysis of discourses in Swedish, Danish and Norwegian health care guidelines for children with diabetes type 1. *Scandinavian Journal of Caring Sciences, 26*(2), 363-371. doi:10.1111/j.1471-6712.2011.00942.x
- Bowes, S., Lowes, S., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with Type 1 diabetes. *Journal of Advanced Nursing, 65*(5), 992-1000. doi:10.1111/j.1365-2648.2009.04963.x
- Callary, B., Rathwell, S., & Young, B. W. (2015). Insights on the process of using interpretive phenomenological analysis in a sport coaching research project. *The Qualitative Report, 20*(2), 63-75.
- Carnevale, F. A., Alexander, E., Davis, M., Rennick, J., & Troini, R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home. *Pediatrics, 117*(1), 48-60. doi:10.1542/peds.2005-0789
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice, 39*(3), 124-130. doi:10.1207/s15430421tip3903_2
- D'Adamo, E., & Caprio, S. (2011). Type 2 diabetes in youth: Epidemiology and pathophysiology. *Diabetes Care, 34*(2), 161-165. doi:10.2337/dc11-s212
- de Oliveira, I. R., Nascif-Júnior, I. A., & Rocha, S. M. M. (2010). Promoting health in families of children with Type 1 diabetes mellitus. *International Journal of Nursing Practice, 16*, 106-111. doi:10.1111/j.1440-172X.2009.01806.x
- Delamater, A. M., de Wit, M., McDarby, V., Malik, J., & Acerini, C. L. (2014). Psychological care of children and adolescents with type 1 diabetes. *Pediatric Diabetes, 15*(S20), 232-244. doi:10.1111/pedi.12191

- Derraik, J. G. B., Reed, P. W., Jefferies, C., Cutfield, S. W., Hofman, W., & Cutfield, W. (2012). Increasing incidence and age at diagnosis among children with Type 1 diabetes mellitus over a 20-year period in Auckland (New Zealand). *PLoS ONE*, 7(2), 1-4, doi:10.1371/journal.pone.0032640
- DIAMOND Research Group. (2006). Incidence and trends of childhood Type 1 diabetes worldwide 1990–1999. *Diabetic Medicine*, 23(8), 857-866. doi:10.1111/j.1464-5491.2006.01925.x
- Etchegary, H. (2010). 'I put it on the back burner most days': Living with chronic risk. *Health*, 15(6), 633-649. doi:10.1177/1363459310364162
- Glenberg, A. M. (2010). Embodiment as a unifying perspective for psychology. *Wiley Interdisciplinary Reviews: Cognitive Science*, 1(4), 586-596. doi:10.1002/wcs.55
- Hamdan, A. (2009). Reflexivity of discomfort in insider-outsider educational research. *McGill Journal of Education*, 44(3), 377-404. doi:10.7202/039946ar
- Hatton, D. L., Canam, C., Thorne, S., & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing*, 22(3), 569-577. doi:10.1046/j.1365-2648.1995.22030569.x
- Health Research Council. (2010). *Guidelines for researchers on health research involving Māori*. Auckland, New Zealand: Health Research Council of New Zealand.
- Horsburgh, D. (2003). Evaluation of qualitative research. *Journal of Clinical Nursing*, 12(2), 307-312. doi:10.1046/j.1365-2702.2003.00683.x
- International Diabetes Federation. (2015). *IDF Diabetes Atlas (7th ed.)*. Brussels, Belgium: International Diabetes Federation.
- Jefferies, C., Owens, N., & Wiltshire, E. (2015). Care for children and adolescents with diabetes in New Zealand District Health Boards: Is the clinical resourcing ready for the challenge? *New Zealand Medical Journal*, 128(1424), 20-27.
- Kelly, S. E. (2005). "A different light": Examining impairment through parent narratives of childhood disability. *Journal of Contemporary Ethnography*, 34(2), 180-205. doi:10.1177/0891241604272065
- Langdrige, D. (2008). Phenomenology and critical social psychology: Directions and debates in theory and research. *Social and Personality Psychology Compass*, 2(3), 1126-1142. doi:10.1111/j.1751-9004.2008.00114.x
- Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., & Gregory, J. W. (2015). The experience of living with Type 1 diabetes and attending clinic from the

- perception of children, adolescents and carers: Analysis of qualitative data from the DEPICTED Study. *Journal of Pediatric Nursing*, 30, 54-62. doi:10.1016/j.pedn.2014.09.006
- Lupton, D. (2012). Infant embodiment and interembodiment: A review of sociocultural perspectives. *Childhood*, 20, 37-50. doi:10.1177/0907568212447244
- Massey, S., Cameron, A., Ouellette, S., & Fine, M. (1998). Qualitative approaches to the study of thriving: What can be learned? *Journal of Social Issues*, 54(2), 337-355. doi:10.1111/j.1540-4560.1998.tb01222.x
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2011). Member checking and Heideggerian phenomenology: A redundant component. *Nurse Researcher*, 18(2), 28-37. doi:10.7748/nr2011.01.18.2.28.c8282
- Mulvaney, S. A., Schlundt, D. G., Mudasiru, E., Fleming, M., Vander Woude, A. M., Russell, W. E., . . . Rothman, R. (2006). Parent perceptions of caring for adolescents with Type 2 diabetes. *Diabetes Care*, 29(5), 993-997. doi:10.2337/dc05-2099
- Power, J., Goodyear, M., Maybery, D., Reupert, A., O'Hanlon, B., Cuff, R., & Perlesz, A. (2015). Family resilience in families where a parent has a mental illness. *Journal of Social Work*, 16(1), 66-82. doi:10.1177/1468017314568081
- Prasad, R. B., & Groop, L. (2015). Genetics of Type 2 diabetes- Pitfalls and possibilities. *Genes*, 6, 87-123. doi:10.3390/genes6010087
- Quirk, H., Blake, H., Dee, B., & Glazebrook, C. (2015). "Having diabetes shouldn't stop them": Healthcare professionals' perceptions of physical activity in children with Type 1 diabetes. *BMC Pediatrics*, 15(1), 1-10. doi:10.1186/s12887-015-0389-5
- Rankin, A., & Lawton, J. (2015). Helping caregivers optimise glycaemic control in children with type 1 diabetes: A qualitative study exploring parents' experiences and views. *Diabetes Care for Children & Young People*, 4(2), 51-55.
- Rintala, T., Paavilainen, E., & Åstedt-Kurki, P. (2013). Everyday living with diabetes described by family members of adult people with Type 1 diabetes. *International Journal of Family Medicine*, 2013, 1-8. doi:10.1155/2013/967872
- Ross, K., Malthus, S., Berrett, M., & Harvey, S. (2009). Providing clinical health psychology services in a primary health world. *New Zealand Journal of Psychology*, 38(1), 39-47.

- Rouf, K., White, L., & Evans, K. (2011). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology and Psychiatry, 17*(1), 49-64. doi:10.1177/1359104511415636
- Sakalys, J. A. (2006). Bringing bodies back in: Embodiment and caring science. *International Journal for Human Caring, 10*(3), 17-21.
- Scambler, S., Newton, P., & Asimakopoulou, K. (2014). The context of empowerment and self-care within the field of diabetes. *Health, 18*(6), 545-560. doi:10.1177/1363459314524801
- Sharma, S., Reimer-Kirkham, S., & Cochrane, M. (2009). Practicing the awareness of embodiment in qualitative health research: Methodological reflections. *Qualitative Health Research, 19*(11), 1642-1650. doi:10.1177/1049732309350684
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54. doi:10.1191/1478088704qp004oa
- Statistics New Zealand. (2013). *Caring for children: Findings from the 2009/10 Time Use Survey*. Retrieved from www.stats.govt.nz.
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with Type 1 diabetes. *Journal of Pediatric Nursing, 18*(1), 21-29. doi:10.1053/jpdn.2003.4
- Sullivan-Bolyai, S., Rosenberg, R., & Bayard, M. (2006). Fathers' reflections on parenting young children with Type 1 diabetes. *The American Journal of Maternal Child Nursing, 31*(1), 24-31.
- Tolman, D. L. (2005). *Dilemmas of desire: Teenage girls talk about sexuality*. Cambridge, MA: Harvard University Press.
- Wennick, A., & Hallström, I. (2006). Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: An ongoing learning process. *Journal of Family Nursing, 12*(4), 368-389. doi:10.1177/1074840706296724
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with Type 1 diabetes. *The Diabetes Educator, 38*, 562-579. doi:10.1177/0145721712445216
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Philadelphia: Open University Press.

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083. doi:10.1177/1049732308320112

APPENDICES

Appendix A: Information Sheet for Participants

Appendix B: Letter Accompanying Information Sheet

Appendix C: Information Flyer for Staff Assisting Recruitment

Appendix D: Study Poster

Appendix E: Interview Schedule

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Appendix H: Preliminary Feedback to Participants, December 2013

Appendix I: Letter from Central Regional Ethics Committee

Appendix A. Information Sheet for Participants



SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North 4442
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673

Family Resilience in Childhood Diabetes

Information Sheet

We would like to invite you to participate in our research looking at how families cope when they have a young child diagnosed with type 1 diabetes. We are interested in finding out what the strengths of a family are that helps them to cope positively when faced with a life challenge, such as a chronic childhood condition like type 1 diabetes.

This research is being carried out by Fathimath Rifshana as part of the Doctor of Clinical Psychology program at the Massey University. The project is supervised by Dr. Mary Breheny, Dr. Kirsty Ross and Dr. Joanne Taylor.

Your participation in this project is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the usual treatment and care. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your future health care or continuing care.

What are the aims of the study?

Our objective is to understand the experience of living with a child with type 1 diabetes and to find out what helps families adjust and cope well in this situation. Findings from the study will help those supporting children and families with chronic health conditions.

Who can participate?

We are interested in talking to families with a child aged between 4-12 years who has been diagnosed with type 1 diabetes for a minimum of six months.

What happens during the study and how long does it take?

Families volunteering to take part in this project will be contacted by the researcher to make an appointment for an interview. The interview will take approximately one to two hours. The interview can be conducted at a place of your choice. A grocery/petrol voucher of \$30 will be presented as a koha for your time as a token of appreciation. The interview involves gathering some general information about your family, and talking about your experience of having a child with type 1 diabetes and what has helped your family in coping and adapting. You do not have to answer all the questions and you can stop the interview at any time. The interview will be audio-recorded and transcribed. A copy of this can be provided to you if you wish.

What are the benefits and risks of taking part in this study?

The experiences you share will contribute to better understand how families cope when facing difficult life challenges, such as a childhood chronic condition, and provide other families with knowledge of strategies

to try. Results from the study will help support families with a child with a chronic illness. Families are welcome to a copy of the interview transcript, and will also receive a summary of the study results if wished.

No safety issues or risks have been identified as a result of taking part in this study. However, if you experience any concerns or experience any negative effects as a consequence of being part of the study, please contact the researcher as soon as possible. Also, if you have any questions or concerns about your rights as a participant in this study, you could contact an independent Health and Disability Advocate. Free phone: 0800 555 050, Free fax: 0800 2 SUPPORT (0800 2787 7678), email: advocacy@hdc.org.nz.

What will happen to the information collected?

All interview data and records will be kept confidential during and after the study. It will be kept in a safe storage at a secure facility for up to 5 years. A subject number will be assigned to each participant. Quotes from the interviews maybe used when reporting the results of this study, but they will be used anonymously. No identifying information will be included in the transcripts of the interviews or in any of the reports that arise from the study.

How can we participate?

If you are interested in taking part in this research or finding more information regarding the project, you can fill out the section on the next page and return it with the postage-paid envelope provided. Alternatively, you can contact the researcher or her supervisor with the details provided below.

Thank you for considering our request.

Yours sincerely,

Fathimath Rifshana
School of Psychology
Massey University
Phone: (06) 356 9099 Ext 2516
Email: rifshana@gmail.com

Project Supervisor:
Dr. Mary Breheny
Senior Lecturer
School of Health & Social Services
Massey University
Phone: (06) 350 5799 Ext 2069
Email: M.R.Breheny@massey.ac.nz

This study has been approved by the Central Regional Ethics Committee on 14 November 2011, reference CEN/11/EXP/085.



Please fill out the details below and send it to the researcher in the postage-paid envelope provided and the researcher will be in touch with you soon.

Name: _____ E-mail: _____

Phone: Home: _____ Work: _____ Mobile: _____

Appendix B. Letter Accompanying Information Sheet



MIDCENTRAL HEALTH

A division of MidCentral District Health Board providing specialist health and disability services

22 May 2012

Phone (06) 356 9169
Fax (06) 350 8818

Postal Address:
Private Bag 11036
Manawatu Mail Centre
Palmerston North 4442
New Zealand

Physical Address:
Ruahine Street
Palmerston North
New Zealand

Dear Child/Family

This letter is to inform you that we met with Fathimath Rifshana, the student undertaking her Doctorate Research in family resilience in childhood diabetes with the School of Psychology at Massey University.

We have agreed to support her in her Doctorate by sending out the information about the study on her behalf in order to maintain your patient confidentiality.

If you have any questions in regards to this study contact details are provided on the information sheet enclosed.

Yours sincerely

MARY MEENDERING
Clinical Nurse Specialist – Diabetes

MM:jk

Diabetes & Endocrinology Service, MidCentral Health, Gate 9, Ruahine Street, Palmerston North 4414, Tel 06-3508114, Fax 06-3508128, Email: diabetes@midcentraldhb.govt.nz

Appendix C. Information Flyer for Staff Assisting Recruitment

Family resilience in childhood diabetes

SCHOOL OF PSYCHOLOGY, MASSEY UNIVERSITY

About this study

- We are conducting a study looking at how families cope when they have a young child diagnosed with type 1 diabetes. We are interested in finding out what the strengths of a family are that helps them to cope positively when faced with a life challenge, such as a chronic childhood condition like type 1 diabetes.
- Our objective is to understand the experiences of living with a child with type 1 diabetes and to find out what helps families adjust and cope well in this situation. Findings of the study will help those supporting children and families with chronic health conditions.
- The experiences shared by families will contribute to better understand how families can bounce back when facing difficult life challenges, such as chronic childhood conditions like type 1 diabetes, and provide other families with knowledge of strategies to try.
- This research is being carried out by Fathimath Rifshana as part of the Doctor of Clinical Psychology program at Massey University. The project is supervised by Dr. Mary Breheny, Dr. Kirsty Ross and Dr. Joanne Taylor (contact details on page 2).

Who can take part in this study?

We are interested in talking to families who fit the following criteria. We would like to interview about 15 families for the study.

- Families with a **child with type 1 diabetes**, aged between 4-12 years
- The time since diagnosis should be at least **6 months**
- Families should be able to understand and speak **English**



Family Resilience in Childhood Diabetes

What does the study involve?

- Families volunteering to take part in this project will be contacted by the researcher to make an appointment for an interview. The interview is expected to take approximately 1-2 hours.
- The interview will be conducted at a convenient location as preferred by the family. A grocery/petrol voucher of \$30 will be presented as a koha for their time.
- The interview involves gathering some general information about the family, and talking about their experiences of having a child with type 1 diabetes and what has helped them in coping and adapting.
- The interview will be audio-recorded and later transcribed verbatim. A copy of this will be provided to the families if they wish.

Contact details

Fathimath Rifshana, Researcher
Phone: 06 356 9099 Ext 2516 or 021 034 3766,
Email: rifshana@gmail.com

Dr. Mary Breheny, Primary Supervisor
Phone: (06) 350 5799 Ext 2069, Email: M.R.Breheny@massey.ac.nz

Dr. Kirsty Ross, Secondary Supervisor
Phone: (06) 356 9099 Ext 81743, Email: K.J.Ross@massey.ac.nz

Thank you!



Appendix D. Study Poster



A study on **family resilience** within **childhood diabetes**

Would you like to be part of a study looking at how families cope when they have a child diagnosed with type 1 diabetes?

We are looking for families with a child:

- who has **type 1 diabetes**,
- aged between **4-12 years**,
- and has been diagnosed for at least **6 months**.

Our goal is to understand the experience of living with a child with type 1 diabetes and to find out what helps families adjust and cope well when faced with a life challenge such as type 1 diabetes.

The study involves an interview with the researcher which will take about 1-2 hours. You will be thanked for your time and efforts with a gift voucher.

If you are interested in taking part in this study, we would like to hear from you. Please ask at the desk for an information sheet.

For further information please contact:

Fathimath Rifshana

Email: rifshana@gmail.com

Tel: 06 356 9099 Ext 2516

This study has received Ethical Approval from the Central Regional Ethics Committee.

Appendix E. Interview Schedule

Family resilience in childhood diabetes: The experience of families with a type 1 diabetic child in New Zealand

Semi-structured Interview Schedule

(DRAFT 4: 3 May, 2012)

Participant number: _____ Date of interview: _____

Questions on family coping with the illness

I am very interested on hearing about your family's experience on how you have been coping and adjusting to the challenges that come with having a child with diabetes. The following questions are meant to stimulate and guide our talk. There may be other questions that come up along the way. Also, please feel free to mention anything else that you think could be important.

1. Tell me about when you first found out that (fill in child's name) had diabetes? How did you know something was wrong? What did you do then?
2. What was the hardest part about it? Why was that difficult for you?
3. How have you come to terms with (x) having diabetes?
4. What worries you the most about (x) having diabetes? Do you have any other worries?
5. We have talked about the challenges in parenting a child with diabetes. What things have you found helpful for coping? Why do you find these helpful? What things are you most thankful for having to help you cope?
6. How do you think you have adjusted and coped with the experience as a family?
7. Are there any good things that came out of this experience? What did you learn as a result of going through this experience?

8. What do you believe are the strengths of your family? Why do you think they are strengths?
9. What advice would you pass onto other families going through the same thing?
10. Is there anything else that you would like to share that we haven't talked about already?

Background information

Now I would just like to ask some questions about your family circumstances. If you would rather not answer these questions, that is fine.

1. Age, gender, ethnicity and marital status of participant _____
2. Relationship to child with diabetes: _____
3. No. of children in the family: _____
4. Age and gender of child with type 1 diabetes: _____
5. Age of child at diagnosis: _____
6. Time since diabetes diagnosis: _____
7. Do any other family members have diabetes? _____

Thank you very much for your time and effort. I appreciate you volunteering to take part in this study and for sharing your experiences with me here today.

Appendix F: Consent Form for Participants



SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North 4442
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673

Family Resilience in Childhood Diabetes

Participant Consent Form

This consent form will be held for a period of five (5) years

I have read and understood the Information Sheet dated _____ for volunteers to take part in the study aimed at understanding the experience of living with a child with type 1 diabetes and finding out what helps families adjust and cope well in this situation. I have had the details of the study explained to me and I am satisfied with the answers that I have been given. I know who to contact if I have any questions or concerns about the study.

I have had time to consider whether to take part in this study. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care or continuing care.

I understand that the interview will be audio-recorded and typed out. No material which could identify me will be included in the transcript or in reports arising from this study.

I agree to participate in this study under the conditions set out in the Information Sheet.

Full Name (Please print): _____

Signature: _____ Date: _____

I wish to receive a summary of the study results mailed/emailed to me: Yes/No

Address: _____

E-mail: _____

Appendix G. Letter Accompanying Transcripts



SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North 4442
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673

Date

Dear (participant),

Re: Family Resilience in Childhood Diabetes Study- Transcript of Interview

It was a pleasure to meet with you and interview you for the study on family resilience within childhood diabetes. Thank you for taking part in the study.

Enclosed is a copy of the transcript of your interview.

You are welcome to read through the transcript and make any additions, deletions or changes you feel as appropriate. If you wish to make any alterations or additions, please make these on the transcript and send it back in the free post envelope. If you would like a copy of the revised transcript, please indicate this wish at the top of the first page. Please feel free to keep the transcript if you do not have any alterations. I will assume that you are happy for me to proceed with the transcript as it stands, if I do not hear from you after three weeks. Please do not hesitate to contact me if you would like to discuss this.

As you are reading the transcript, please keep in mind that the way we talk is often very different from the way we write. It is natural to say lots of ums and aahs, to repeat ourselves, or to leave sentences unfinished when we are speaking, and the transcript will reflect this. It is a common response to feel uncomfortable when reading through one's transcript, so please do not be uneasy when you read over what you have said.

I would also like to point out that the transcript includes names, places and other such details that you mentioned in the interview, as this makes the transcript easier to read. Please be assured that these will be removed before any quotes from your transcript are used, as your confidentiality is important to us.

Once again, thank you for your support and for being part of this research.

Yours sincerely,

Fathimath Rifshana
Doctor of Clinical Psychology Student
Massey University
Palmerston North
Ph: 06 356 9099 ext 2516, Cell: 022 200 5762

Appendix H. Preliminary Feedback to Participants, December 2013



FAMILY RESILIENCE IN CHILDHOOD TYPE 1 DIABETES

Dear

Thank you for taking part in the study on the experience of parenting a child with Type 1 diabetes. The experiences you have shared are invaluable in expanding our understanding of what it is like to care for a child with Type 1 diabetes. I am writing to give you a brief update on the results so far.

THE RESEARCH

In 2012, I interviewed 17 parents from the Manawatu, Wanganui and Hawke's Bay regions parenting a child with Type 1 diabetes. Their children with diabetes were between the ages of five to 12 years. The duration of illness ranged from nine months to nine and a half years. I also interviewed five health professionals who were supporting families of children with Type 1 diabetes, to obtain their perspectives on the topic. This year I have been analysing the transcripts of the parents' interviews. Analysis is still on-going, but at this point I can provide a brief summary of findings to date.

PRELIMINARY FINDINGS

The interview aimed to explore the lived experience of parents as they care for a child with Type 1 diabetes. During the interviews, parents voiced their concerns, worries and insights into living with this chronic childhood condition. Some of the main recurring themes through the parents' accounts were:

Constant vigilance and surveillance: Parents described the experience of looking after their child with diabetes as governed by the need for constant vigilance. Parents needed to continuously monitor the child to ensure their blood sugar readings remained within the healthy range, whilst balancing the child's diet, activity and insulin dose. Planning was a large part of this vigilance, although often-times parents found themselves disappointed with unexpected results even with the best planning. This unpredictability of blood sugars often cast a shadow over the parents' attempts at managing the condition. Parents attempted to make sense of this unpredictability in various ways, such as taking into account factors such as the child's emotions and individual differences, in their continued efforts to understand and manage their child's condition.

The "constant-ness" of diabetes showed the chronic and pervasive nature of this condition. Parents struggled with the lack of a cure in diabetes which caused continuous grief for them. In addition, parents described the public awareness and sympathy that is present for some childhood conditions such as cancer, which seems to be lacking for Type 1 diabetes and can act as a barrier to external support.

In pursuit of normality: Maintaining normality was one of the ways that parents sought to incorporate diabetes into their lives. Parents tried to provide their child with typical childhood experiences, although they faced tensions in doing so. Parents described how diabetes impacts on childhood through challenging a child's freedom, the loss of spontaneity, the regimented life, increased level of responsibility and pressure to make good choices now to ensure access to a secure future. Despite these, parents attempted to be flexible with meeting their child's diabetes needs so that they could still take part in birthday parties, sleepovers and other childhood experiences. Parents describe the importance of this to help their child feel like everyone else. Parents also attempted to maintain normality through disciplining practices, but this often involved the additional challenge of distinguishing blood-sugar-related misbehaviour from age-appropriate misbehaviour.

Some parents went further in their attempts to maintain normality by redefining what normality meant for their families. In this way, the requirements of diabetes were the new normal for their families. This was supported by connecting with other individuals and families affected by the condition with whom the requirement of diabetes was shared. Shared experience was described as a key way of validating their experiences, proving reassurance and supporting normality. Although these two strategies of providing access for the child with diabetes to normal childhood experiences and changing the family environment to a diabetes supportive environment sought to maintain normality, parents also described the need to balance these two approaches.

These preliminary results point to the hardships and difficulties in caring for a child with Type 1 diabetes and the various tensions that parents need to manage on a daily basis. They also highlight the strength and resilience of the parents, as they looked for different ways of coping with the illness that would work for the whole family.

WHAT'S NEXT

I will be on maternity leave in 2014, and will return to completing the research after that time. When the study is completed, I will send you a final summary of findings. I will also provide the results and recommendations to the support agencies and professionals who have been involved with the study. I hope the findings of this research will be beneficial in improving the help and support provided for children with Type 1 diabetes and their families.

Thank you for your participation in this research and for the time and effort spent in sharing your experiences with me. If you have any questions or would like any further information regarding the project, please do not hesitate to get in touch with me or my primary supervisor, using the contact details provided below.

Wishing you a merry Christmas and a happy New Year.

Yours sincerely,

Fathimath Rifshana
School of Psychology
Massey University
Palmerston North
Email: rifshana@gmail.com
Phone: +64 6 356 9099 ext.85588

Primary Supervisor:
Dr Mary Breheny
Senior Lecturer
School of Health & Social Services
Massey University
Palmerston North
Email: M.R.Breheny@massey.ac.nz
Phone: +64 6 356 9099 ext.83523

Page 2 of 2

Appendix I. Letter from Central Regional Ethics Committee



Central Regional Ethics Committee
c/- Ministry of Health
PO Box 5013
1 the Terrace
Wellington
Phone: (04) 816 2405
Email: central_ethicscommittee@moh.govt.nz

14 May 2012

Ms Fathimath Rifshana
Psychology Clinic
PO Box 11 222
Massey University
Palmerston North

Dear Ms Fathimath Rifshana

Ethics ref: CEN/11/EXP/085 (please quote in all correspondence)
Study title: Family Resilience in Childhood Diabetes: The Experience of Families with Type 1 Diabetic Child in New Zealand
Investigators: Ms Fathimath Rifshana, Dr Kirsty Ross, Dr Joanne Taylor, Dr Mary Breheny

The Central Regional Ethics Committee considered and approved an amendment to your study on 7 May 2012.

Approved Documents

- Information Sheet: Family Resilience in Childhood Diabetes. Version 2, dated 3 May 2012
- Participant Consent Form. Version 2, dated 3 May 2012
- Poster: Family Resilience in Childhood Diabetes
- Flyer: A Study on Family Resilience within Childhood Diabetes
- Family Resilience in Childhood Diabetes: The Experience of Family with Type 1 Diabetic Child New Zealand. Semi-Structured Interview Schedule, Draft 4, dated 3 May 2012
- Dr Mary Breheny, Primary Supervisor

Please do not hesitate to contact me should you have any queries.

Yours sincerely

Administrator
Central Regional Ethics Committee
Email: central_ethicscommittee@moh.govt.nz